INSIGHT INTO INSIGHT: A STUDY ON UNDERSTANDING IN SCHIZOPHRENIA

A Thesis Submitted in Partial Fulfilment

of the Requirements for the Degree

of

Doctor of Philosophy

by

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ABSTRACT

The lack of insight into their illness continues to be a significant barrier to treatment for people with schizophrenia. However, some people with the illness do develop insight which then results in stability and recovery from their condition. Having met the criteria of good insight, nineteen participants participated in semi-structured interviews exploring the concept of insight and recovery in the context of their personal experiences. Research design used grounded theory methodology layered with a further narrative analysis. The literature review and theoretical perspectives of care provide the context for the research, thus illuminating the known and determining what mysteries in insight development remain.

Study findings revealed a *Paradox of Insight* within a 3-stage process of insight development: *The Period of Chaos, the Dynamic Period,* and the *Period of Wisdom*. An overarching *Theory of Dangerousness* explains the turning point from illness to recovery. This turning point occurs with a *Trinity of Crisis*. Within this theory, *Four Constructions of Dangerousness* explain how the meaning making of dangerousness affects recovery. Additionally, *Four Types of Insight* support this recovery.

The importance, meaning, and relevance of study findings for recovery are the focus of the discussion. Six inter-rator focus groups affirmed the findings. Policy and practice implications are discussed, along with recommendations for further research and the acknowledgement of study limitations.

KEY WORDS

insight, danger, recovery, schizophrenia, chronic illness, event, crisis, resilience, spirituality, support

CHAPTER ONE CONCEPTIONS OF THE RESEARCH

1.1 Introduction

Chapter One outlines how this particular research project on developing insight and understanding in schizophrenia was conceptualized, identifies the aims of the research, and outlines the thesis structure.

My maternal grandmother, Lydia Hardie, was a woman with schizophrenia, and while I did not know her well, I was curious about how her illness influenced my own mother. As a social worker, I developed my career in mental health practice in an inpatient psychiatric unit in our community hospital. This experience inflamed my interest in schizophrenia and insight as I observed the denial, cycles of relapse and hospitalizations, family dynamics, and the meaning patients make of their own illness as it unfolds. I became intensely curious about a process of recovery that starts with bringing people to their knees. Coupled with this interest were my goals for life-long learning, and, as a result, I decided to study for a PhD in clinical social work.

I had many reasons for applying for study at the University of Canterbury in New Zealand, despite being a Canadian living and working in Canada. Canadian PhD models of social work education are somewhat limiting, with few part-time models of study available. The one that suited best at the time was geographically at the opposite end of our large country from where I reside in British Columbia. If I had to travel that far, I decided I might as well see a different country. In addition, my husband was semi-retired and anxious to begin travelling, so a study/travel opportunity served us both well. I applied to the University of Canterbury in New Zealand and after

negotiation with the School of Social Work and Human Services, my study proposal was accepted, with two provisos: that I serve two residency periods in New Zealand over the course of my study, and that I obtain a clinical supervisor in Canada. Agreement was reached, and in 2006, I embarked on PhD preparation in clinical social work.

The people in the mental health community both in Canada and New Zealand have been supportive of my studies. Following ethics approval, recruitment was not an obstacle, and with all in place, I initiated the study. The Canadians furnished all of the participants for my study, and both Canadian and New Zealand mental health professionals provided me with inter-rator focus groups. These focus groups assisted me from the initial research design phase to provision of feedback on the final analysis of the study findings.

"Getting at" the why and how of insight development seemed best suited to qualitative research methodology. Qualitative research does not approach the research with a hypothesis, but allows the hypothesis to be garnered from the research. This explorative approach appealed to me, as it allowed me to have conversations with people who have insight. These conversations were based upon semi-structured interview questions that produced huge amounts of data. The data collection then lent itself to developing a theory to explain and predict insight development.

1.2 Aims and Objectives of the Research

From the outset, my curiosity about an insight process existed, and perhaps even more importantly, I wondered if there was a process to insight development, and what specifically provoked this or explained this level of recovery. I planned to explore the literature on insight development, review the recovery models, and assess the many ideologies that drive mental health practice.

The aims of the research include:

1. To determine if a process to insight exists.
2. If a process exists, are there stages in the process?
3. If there is a process, what exactly, triggers the process?
4. What maintains recovery or provokes relapse?
5. Are there factors within insight development?
6. What theory can be derived from the study findings to predict, explain, and direct practice?
7. How can the information provided by the participants be best conveyed and utilized?
8. What is the best way to convey the findings to others?

I set two objectives for the study. Firstly, that my work does justice to the time, energy, voices, and stories participants gave to the study. Secondly, that the study findings further mental health professionals' insight into the construct of insight in people with schizophrenia. These aims and objectives explain the investigative aspect of the research title, *Insight into Insight: A Study on Understanding in Schizophrenia*.

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1.3 Structure of the Thesis

Social work has long borrowed the adage from feminist literature that the "Personal is Political". Social workers are in a unique position to "recognize the interplay between the personal characteristics and the environmental factors" (Smart & Smart, 2006, p. 37) at work in the development of an individual. Good social work focuses on the individual needs of the client, but does not ignore or isolate the person from the environment in which they live. The environmental, or ecological domain includes the immediate psychosocial environment of the person and extends to the larger contextual structures of economics, culture, and politics. Social workers who cannot or will not examine and tackle these larger environmental pressures upon the individual take a "head in the sand" approach to their work and neglect the importance and influence of macro structures in their interventions with clients.

Structured to address and define the individual problems of the client with schizophrenia, this thesis also examines the impact of the individual's illness on his or her family and larger social circle. This thesis addresses the relationship between effects of the illness on society, and conversely, and perhaps more importantly, how societal decisions may have an impact on the person with the illness.

Chapter One has supplied information on the conceptualizations, aims, and outcomes of the research and now presents the remaining structure of the thesis.

Chapter Two introduces and describes schizophrenia, and then examines the aetiology and prevalence of the illness.

Chapter Three provides the rationale for the study and details the burden of care on families and society and describes the problems associated with the illness, such as stigma, medication non-adherence, substance abuse, and violence.

Literature abounds on the concept of insight. Therefore, a comprehensive literature review on the lack of insight is the focus of Chapter Four with the aim of defining, describing, and addressing questions of prevalence, and introducing constructs and recovery models associated with insight.

Chapter Five outlines historical and ideological theoretical perspectives of schizophrenia and examines the rights of the individual with schizophrenia.

Chapter Six, the methodology chapter, explains the rationale for grounded theory methodology and describes the research design, ethics approvals, and application of the methodology in this thesis.

Chapter Seven introduces the participants to the reader and presents their demographical composition.

Chapters Eight, Nine, Ten, and Eleven describe the findings of the study. Chapter Eight explains the *Period of Chaos*, the paradoxical stage of insight development. Chapters Nine and Ten describe the active *Dynamic Period* of insight development, while Chapter Eleven portrays the *Period of Wisdom* that completes the insight process.

Chapter Twelve presents the findings of three of the *Four Phenomena of Influence* that permeate the process and have the potential to both impede and facilitate the insight process. The fourth influence, and the strongest finding of the study, spirituality, is the focus of Chapter Thirteen.

Layering a narrative analysis over a grounded theory analysis provided some validity to the study findings. Chapter Fourteen is the narrative analysis of the stories delivered by the participants around their turning points.

The meaning of the findings is the focus of the discussion in Chapter Fifteen. A *Theory of Dangerousness* is presented, and the constructions of that theory are highlighted in a discussion. The *Theory of Dangerousness* also insists on a discourse on the ideological aspects of care provided to those with schizophrenia.

Derived from the findings, implications for policy and practice are evident. Chapter Sixteen discusses these implications, and like most research, raises more questions than it provides answers. Therefore, recommendations for further research are included along with acknowledgement of the limitations of the research and some concluding statements.

1.4 Conclusion

Chapter One has set the stage for the reader of this research project. It has described how the research was conceptualized by my own family experience with schizophrenia and my practice experience with this population group. In addition, Chapter One has identified the aims of the research project to determine if a process

in the development of insight exists, and if so, to explore all the factors that instigate, promote, and maintains insight and recovery. Finally, Chapter One has outlined for the reader the chapters and structure of the thesis. Chapter Two now introduces the problem, provides some historical perspective and some contextual biopsychosocial formulations on the aetiology of the illness.

CHAPTER TWO INTRODUCTION TO THE PROBLEM

2.1 Introduction

Chapter Two provides an introduction to, and explores the historical context of the problem of schizophrenia, as well as some contextual information on the genetic, biological, and environmental formulation of its aetiology. In addition, it examines the contribution of ethnicity and vulnerability. Finally, it discusses the prevalence of the illness and the impact it has on gender.

Schizophrenia's dubious distinction is that it is the most chronic, debilitating, and costly of all mental illnesses. Narratives supplied by people with schizophrenia paint pictures of the extent of suffering brought on by the illness. Geanellos (2005) captures many elements of this in her narrative study that describes the distressing losses: feeling fragmented, desperately trying to appear normal, the anguish of suffering alone, stigmatization, slowly deteriorating relationships, feeling afraid, confused and bewildered, feeling overwhelmed by daily life, feeling disconnected from self, others, and the world of reality. Patients report fighting for their survival, going it alone, getting control of their stories, making a narrow escape, and battling a corrupt system (Thornhill, Clare, & May, 2004). Their hospitalization experiences are described as damaging, dehumanizing, and oppressive (Bassman, 1997, 2000). France and Uhlin (2006) refer to narratives that describe "frightening psychotic symptoms" (p. 60). In a personal narrative, Pfeifer (1970) eloquently illustrates the agony suffered from her hallucinations: "taut, cutting pain, frustrating, incapacitating, vastly frightening and devastating, disturbing guilt, panic stricken, stupor, bizarre, tormenting, discomfort, sadness and aura of evil" (pp. 57-60).

Schizophrenia is a mental disorder invariably characterized by a condition called psychosis. In fact, psychosis often forebodes the onset of schizophrenia disorders (Canadian Mental Health Association, 2004). Psychosis embodies gross impairments in reality testing and severe disturbances in perception, cognition, behaviour, and feeling. It has multiple causal factors, including substance abuse and/or withdrawal, exposure to severe stress, medical conditions, and mood disturbances. Usually presenting in early adult life, schizophrenia's one-year and lifetime prevalence rates are estimated at 0.34 per 100 and 0.55 per 100 respectively (Goldner, Hsu, Waraich, & Somers, 2002) and represents about 1% of the global burden of disease (World Health Organization, 1996). Although a chronic condition, bouts of acuity account for 22% to 25% of all mental health costs in the United States (Thieda, Beard, Richter, & Kane, 2003). Moreover, the diminished work capacity and inability to sustain employment (Russinova, Wewiorski, Lyass, Rogers, & Massaro, 2002) create a substantial poverty risk for people with the illness (Ruesch, Graf, Meyer, Rossler, & Hell, 2004). While treatment for schizophrenia is available, people often lack insight into their illness, which directly affects their ability to cooperate with the treatment; people with schizophrenia often do not adhere to treatment or flatly refuse treatment (Cuesta, Peralta, & Zarzuela, 2000; Keshevan, Rabinowitz, DeSmedt, Harvey, & Schooler, 2004; Koren et al., 2004; McCabe, Quayle, Beirne, & Duane, 2000; Rossi et al., 2000). An abundance of literature describes and measures this lack of insight, but a surprising paucity of research exists on how insight is actually developed. As effective practice techniques for the chronically mentally ill "are interdisciplinary in design and application" (Hogerty, 1989, p. 370), this research integrates the disciplines of social work and medicine in order to study the process of insight development.

2.2 History of Schizophrenia

The historical underpinnings and social construction of an illness are essential to its understanding. Understanding the social construction of the illness involves understanding how illness affects the patient and the ways in which the identification of experiences and behaviours as illness reflect, to some degree, social attitudes and beliefs. These attitudes and beliefs emerge in a historical as well as cultural context. It may also be reasonable to say that the relationship between mental illness and social attitudes and beliefs is more intimate than that for other illnesses, and that the social context more strongly influences the care and treatment of the insane. Some commentators go so far as to argue that mental illness can only be defined within a specific historical time and social context (Mulder, 1993, p. 557).

Ancient physicians, as early as ancient Egypt and the second millennium before Christ (Adityanjee, Aderbigbe, Theodoridis, & Vieweg, 1999; Alexander & Selesnick, 1966) deemed psychosis to be a physical illness of the heart and uterus originating in the blood vessels or from "purulence, fecal matter, a poison or demons" (Carlsson, 2005, p. 1). Greek physicians blamed delusions and paranoia on a lack of harmony between bodily humours of blood, phlegm, and yellow or black bile (Alexander & Selesnick, 1966; Carlsson, 2005; Evans, McGrath, & Milns, 2003; Roccatagliata, 1991). Hippocrates supposed these humoural imbalances influenced (Carlsson, 2005; Fabrega, 1990) or corrupted the brain (Evans et al., 2003), and, therefore, the biological constitution of human beings caused insanity (Micale & Porter, 1994).

From the 12th to the 14th century, town records in Europe substantiate that forceful banishment of the mentally ill was practised as the "madman tended to be equated with paganism, demonic origins and the countryside" (Fabrega, 1990, p. 300). Seen as a type of ape-man with a subhuman mentality (Dols, 1984), "the rural madman was a neglected and an often mistreated nomad, a starving and sometimes abused beggar" (Neaman, 1975, p. 135).

Early Christian saints "blessed" with voices and visions may have been, in fact, people with schizophrenia, but their experiences were considered divine rather than demonic (Heinrichs, 2003; Porter, 1987). This belief declined in 15th century Europe when hallucinating and delusional women were deemed witches and burned at the stake (Alexander & Selesnick, 1966; Heinrichs, 2003; Levine, 1981; Micale & Porter, 1994). By the end of the 15th century, "magical remedies against supernatural harm, such as astrological amulets, charms and exorcisms, were discarded by reputable practitioners" (Macdonald, 1981, p. 10).

Institutionalization of people exhibiting symptoms of schizophrenia gained popularity in the 16th century (Levine, 1981; Macdonald, 1981). As asylums flourished, flogging with chains and the use of stocks (Alexander & Selesnick, 1966) were employed to quell symptoms and teach inmates good behaviour (Macdonald, 1981). In 17th century Europe, the field of psychiatry was born, and special hospitals were created for mental patients. Often squalid, they were open for viewing by the public to "gawk at the small company of lunatics" (Macdonald, 1981, p. 122).

In 1967, Sir Audrey Lewis, the distinguished senior psychiatrist of the Maudsley Hospital, summed up the ignorance of the past and the hope for the mentally ill that began in the 19th century:

> After the tortures and judicial murders of the Middle Ages and the Renaissance, which confounded demoniacal possession with delusions and frenzy, and smelt out witchcraft in the maunderings of demented old women, there was the cruelties and degradation of the madhouses of the seventeenth and eighteenth centuries, in which authority used chains and whips as its instruments. Humanitarian effort put an end to such abuses. Pinel in France, Chiarugi in Italy, Tuke in England inaugurated an era of kindness and medical care which prepared the way for a rational, humane approach to the mastery of mental illness. In the 19th century the pathology of insanity was investigated, its clinical forms described and classified, it kinship with physical disease and the psychoneuroses was recognized. (Micale & Porter, 1994, p. 6)

Slowly, the ignorance of the past gave way to more effective treatment for the mentally ill.

In 1889, German physician Emil Kraepelin coined the term *dementia praecox* to describe the symptoms currently associated with schizophrenia. The term *dementia* became useful to describe the global disruptions he observed in perceptual and cognitive functioning, while *praecox* referred to the onset of the disorder in early adulthood (Adityanjee et al., 1999; Alexander & Selesnick, 1966; Micale & Porter, 1994; Neale & Oltmanns, 1980; Porter, 1987).

In 1911, Swiss psychiatrist Eugene Bleuler coined the word *schizophrenia* to describe the disorder (Alexander & Selesnick, 1966; Maj & Sartorius, 1999). Derived from the Greek root words *schizo*, meaning split, and *phrene*, meaning mind, the "split" refers to the split or fragmentation of the thinking (Adityanjee et al., 1999; Alexander & Selesnick, 1966; Davison & Neale, 1998), the split between subjective feelings and thoughts being experienced (Walters, 2005), or to indicate a split in psychic

functioning (Alexander & Selesnick, 1966). Also, Bleuler was the first to describe the positive symptoms (delusions, hallucinations, and disorganized speech or behaviour) and negative symptoms (affective flattening, alogia, and avolition) of the illness (Adityanjee et al., 1999).

2.3 Aetiology

Two theories of aetiology exist: the biological model and the environmental model. Both models will be fully addressed in this following section.

2.3.1 Biological Models

Biological models of schizophrenia include the genetic model (Baron, 2001; Freedman, Ross, & Adler, 2005; Myles-Worsley, 2002; Tsuang, Gilbertson, & Faraone, 1991; Xi et al., 2004), the neurotransmitter model (Carfagno, Hoskins, Pinto, Yeh, & Raffa, 2000; Kahn & Van Kammen, 2000; Stober et al.,1998), and the executive function model (Fucetola et al., 2000; Silver, Feldman, & Gur, 2003; Szeszko, Goldman, Knuth, & Bilder, 2002; Velligan & Bow-Thomas, 1999).

2.3.1.1 Genetic Model

Genetic research has mounted evidence for genetic transmission of the illness (Cannon, Kaprio, Lonnqvist, Huttunen, & Koskenvuo, 1998; Egan, 2004; Leonard et al., 2002; Mimmack et al., 2002; Myles-Worsley, 2002; Satcher, 1999; Volavka, Bilder, & Lachman, 2004), although risk ranges vary in the literature. First-degree biological relatives (parent, sibling, or offspring) of people with schizophrenia are 3% to 7% more likely to develop the disease than the general population (Jones &

Cannon, 1998). A higher lifetime risk of 5% to 10% exists for first-degree relatives including siblings and children (Cannon et al., 1998). Risk increases to 13% for a child with one parent with schizophrenia and swells to 35% to 40% for a child with two parents with schizophrenia (Lee, McGlashen, & Woods, 2005).

Genetic factors account for about 60% of one's liability to develop schizophrenia, and concordance rates for schizophrenia between monozygotic twins range between 40% and 70%. Glutamate is a key neurotransmitter suspected of playing a role in schizophrenia (Yank, Bentley, & Hargrove, 1993). The gene that makes GRM3, a receptor responsible for regulating glutamate in synapses where glutamate transfers information from cell to cell, is a promising schizophrenia candidate gene (Eagan et al., 2004). Rioux and Arnold (2005) found that the proportion of granule cells of the dentate gyrus expressing RARalpha is doubled in schizophrenia. Psychiatric Genomics (2004) report that the "expression levels of genes encoding for every metabolism and protein processing were selectively and consistently decreased in the brains of patients with schizophrenia" (p. 1). Strong evidence for schizophrenia susceptibility loci relates to genes encoding dysbindin and neuregulin (Norton, Williams, & Owen, 2006), while abnormal mitochondrial function has been found in people with schizophrenia (Gardner & Boles, 2005). In a meta-analysis, Philibert (2006) found a strong association between the presence of the HOPA gene and a risk factor for schizophrenia. Catechol-O-methyl tranferase (COMT) gene is also a promising schizophrenia susceptibility gene leading to poor prefrontal functions in working memory (Oshishi et al., 2006). It is now generally accepted that genetics participate substantially in schizophrenia aetiology.

2.3.1.2 Neurotransmitter Model

The neurotransmitter model is one of the "earliest, most enduring and most influential of the modern neurochemical theories of mental illness" (Baumeister & Francis, 2002, p. 265). This model focuses on chemical transmission in the prefrontal cortex, hippocampus, and temporal lobes of the brain. It postulates "that increased dopamine receptor activity in these areas results in hallucinations and delusions" (Beebe, 2003, p. 67). Dopamine dysfunction could be the primary mechanism for the elaboration of delusions and delusional perceptions (Lecrubier & Kapur, 2005). Increased levels of glutamate in the prefrontal and limbic brain have been found in people with schizophrenia (Van Elst et al., 2005). Increased prefrontal glutamate concentrations have also been associated with poorer global functioning. Over time, research has shifted from the study of neurotransmitter changes to the study of how a neurotransmitter system interacts with other brain systems, thus affecting current conceptualizations of the neurotransmitter model. There appears to be an interaction between the role of dopamine within the neurobiology of the brain, the phenomenological experiences of the mind, and the pharmacological aspects of psychosis in schizophrenia (Kapur, 2003). Researchers have found dopaminergic abnormalities in the thalamus in schizophrenia (Clinton et al., 2005). In fact, antipsychotic medication acts as a dopamine receptor blockade (Carlsson, Carlsson, & Nilsson, 2004). Grignon and Chianetta's (2007) meta-analysis found that oxidative stress, as evidenced by peripheral lipid peroxidation, is indicative of significant pathophysiological disturbances. Kammen (2000) alludes to the pending "clarification of the genetic underpinnings of these complex disorders and their altered biochemistries" (p. 2), which may affect how the neurotransmitter model is viewed.

2.3.1.3 Executive Function Model

Executive function models endeavour to explain schizophrenia as a dysfunction in the prefrontal brain resulting in neurocognitive deficits (Amador et al., 1994; McGrath, Scheldt, Weldham, & Clair, 1997; Suzuki et al., 2005; Turner, Fedtsova, & Jeste, 1997). These deficits affect ability in "ordering sequential behaviours, establishing goal-directed plans, maintaining task when interrupted, monitoring personal behaviour, and associating knowledge with required responses" (Beebe, 2003, p. 68). However, while there is a relationship between poor insight and cognitive impairment, these may not be specific to frontal lobe dysfunction (Goodman, Knoll, Isakov, & Silver, 2005). Neuropsychological dysfunction, specific to impairment of set shifting and error monitoring, contributes to poor insight in psychosis (Aleman, Agrawal, Morgan, & David, 2006). Hippocampus abnormalities (Szeszko et al., 2002) and lower error related activity in the anterior cingulate cortex are hypothesized to craft disturbances that alter executive function (Alain, McNeely, He, Christensen, & West, 2002; Carter, MacDonald, Ross, & Stenger, 2001; Dehaene et al., 2003; Heckers et al., 2004; Laurens, Ngan, Bates, Kiehl, & Liddle, 2003). In addition, researchers have found the presence of reduced anterior cingulate volumes in schizophrenia (Baiano et al., 2007). White matter abnormalities are linked to early onset schizophrenia and may contribute to deficits in motivation, attention, memory, and higher executive functions in adolescents (Kumar et al., 2005). Cellular level loss or reversal of asymmetry is consistent with the hypothesis of a primary change in the relative development of areas of heteromodal association cortex in the two hemispheres (Cullen et al., 2006). As memory significantly correlates with insight (Chen et al., 2005), structural abnormalities may impair insight development.

Andrews, Wang, Csernansky, Gado, and Barch (2006) find limited relationships between morphological and functional abnormalities of the thalamus in schizophrenia and argue for continued research on the link between brain structure and function in schizophrenia. A relationship between insight deficits and cognitive function and the frontal and parietal cortex has also been found (Shad, Tamminga, Cullum, Haas, & Keshavan, 2006). In a meta-analysis, cognitive deficits between healthy control subjects and people with schizophrenia were compared, and a consistent trend was identified. People with the illness showed cognitive deficits in all five domains of cognitive function: memory, language, executive function, attention, and IQ (Fioravanti, Carlone, Vitale, Cinti, & Clare, 2005).

The Theory of Mind (TOM) is a fascinating executive function theory that refers to the lack of capacity to infer one's own and other people's mental state, or more simply, one's ability to "think about thinking" (Frith, 1992). Corcoran (2003) refers to TOM as a form of inductive reasoning in which we draw on information gathered in the past to inform our current problems. People with schizophrenia have specific difficulties in inferring what others "intend, think or pretend, and this TOM impairment probably influences the way schizophrenia patients use language and interpret speech" (Brune, 2005, p. 37). It is precisely the brain areas involved in TOM that are frequently found to be abnormal in people with schizophrenia: the prefrontal cortex and the temporal cortex. Speculatively, the deterioration of the TOM is due to "some unknown neuropathological process" (Brune, 2005, p. 37) that may account for many positive and negative symptoms of schizophrenia. In one study, some people with active delusions had no insight until the interview perspective shifted from a first person focus to a third person focus, thus suggesting that thinking about their own

thinking may be impaired (Gambini, Barbeiri, & Scarone, 2004). While executive function models that include TOM are possible explanations, the question remains as to whether executive function difficulties are the result of neurocognitive deficits (Lysaker, France, Hunter, & Davis, 2005) or an expression of genetic statements. The review of the genetic model, neurotransmitter model, and the executive function models give a clearer picture of the complicated search for a biological aetiology for the illness. Yet, environmental models cannot be ruled out as contributory.

2.3.2 Environmental Models

Mid-20th century research ushered in environmental constructs of aetiology based on family dynamics, ethnicity, vulnerability, and trauma. These environmental constructs will be discussed in this next section.

2.3.2.1 Family Dynamics

Frieda Fromm-Reichmann often blamed the mother-child relationship, specifically, the *schizophrenogenic mother* for provoking the illness (Neill, 1990). In the mid-1950s, Bateson extended this notion and proposed the Double-Bind hypothesis. Essentially, he hypothesized that an intense relationship with another person (the mother) who expresses two contradictory messages leaves the recipient of the messages (the child) unable to explain the contradiction and, therefore, is forced to withdraw from the situation, or to ignore the messages. The second message contradicts the first and is often enforced with punishment. This "can't win"or "double bind" has been theorized to create the illness (Bateson, Jackson, Haley, & Weakland, 1956, 1963; Visser, 2003).

Meehl (1962) judged that the genetic risk was under-appreciated as an aetiological clue to schizophrenia (Freedman et al., 2005; Schizophrenia Homepage, 2005). While not excluding the environmental possibility, Meehl posited that the disease was an interaction of genetics and environment. He emphasized schizotaxia, or the neural integrative deficit, as the inherited factor in the development of the disease. Schizotaxia interacts with what the individual learns from the environment and forms a personality organization called a schizotype. While thought disorder, interpersonal aversiveness, anhedonia, and ambivalence are learned by schizotaxic individuals, only a small number actually develop schizophrenia (Meehl, 1962).

The first gift a family bestows on its offspring is his or her genetic makeup. The second gift is the environmental milieu shoring up the child's development (Canavan, 2000). Environmental factors, such as viral exposure, nutritional deficiencies, foetal growth restrictions, and obstetric complications, may be aetiologically linked to schizophrenia (Geddes & Lawrie, 1995; Nilsson et al., 2005; Schultz & Andreasen, 1999; Verdoux et al., 1997), but poorly predict development (Moldin & Gottesman, 1997). While a genetic component to aetiology exists, epidemiological data verifies the importance of environmental factors on normal and pathological development (Reiss, Plomin, & Hetherington, 1991). A Finnish study of adopted out offspring of mothers with schizophrenia found that no cases of schizophrenia developed in offspring adopted into families considered healthy or only mildly disturbed, while of those offspring who were psychotic, nearly all were raised in disturbed adopted families (Tienari et al., 1987), thus providing possible evidence of the interaction between genetic factors and the environment.

Monozygotic twin pairs share duplicate genetic material, yet low monozygotic twin concordance rates for psychiatric illness have been found (Canavan, 2000). As many as 50% of monozygotic co-twins are unaffected by schizophrenia which "clearly points to the importance of environmental factors in the origin of these disorders" (Jones & Cannon, 1998, p. 2). Conversely, siblings sharing the same familial environment may be expected to share the same psychiatric outcomes, but concordance rates for siblings and psychiatric illness are lower than 10% (Gottesman & Shields, 1982; Rice et al., 1987). Jarvis (2007) conducted a review of North American literature to help clarify mechanisms underlying poverty, migration, and racial discrimination that contribute to mental illness. He found substantial scholarly neglect in this area and hypothesizes this may be due to the rise of genetic-biological paradigms to explain mental illness. Accumulating evidence from migrant studies demonstrates that social factors play a role in the development of schizophrenia, but the mechanism by which social factors exert their influence is as yet unknown (Cantor-Graae, 2007). Jarvis (2007) notes a paucity of literature on the social causes of psychosis and challenges North Americans to address these social factors. Environment can neither be discounted, nor considered solely liable as the primary factor in disease aetiology.

2.3.2.2 Ethnicity

Ethnicity, which includes culture and race, may participate in the prevalence of schizophrenia. However, defining ethnicity remains a serious problem (Bhugra et al., 2000). Lopez and Guarnaccia (2000) caution researchers to be critical of how culture is conceptualized, as conceptualizations guide research. They suggest that culture cannot be treated as an independent factor and, therefore, researchers must consider

how social forces such as class, poverty, and marginality affect culture. Social class of origin is associated with positive symptoms of schizophrenia over the early illness course (Brown, Susser, Jandorf, & Bromet, 2000). Psychiatry has "been justifiably accused of racism" (Knowles, 1991, p. 173) for applying Western diagnostic categories deemed inadequate for identifying mental pathologies in different cultural contexts (p. 186). It may, in fact, be "Eurocentric" (Saravanan et al., 2004, p. 107) as, "the DSM-IV is itself a cultural document, infused with many culturally based assumptions" (O'Connor & Vandenberg, 2005, p. 610). Jenkins and Barrett (2004) argue against the notion that schizophrenia is acultural, a state without agency or subjectivity. Cultural differences do exist, yet the literature has not yet determined if race predisposes a person to the illness or if illness is a response to the social environment in which the person of race is steeped.

Three paradigm shifts challenge the concept of "ethnicity". Firstly, an ethnic group in one setting is not necessarily generalizable to similar populations in other countries. Secondly, simplistic ethnic groupings or "race" based research variables have evolved toward sophisticated categories of "identity" and "cultural groups" in conjunction with assessment of socio-economic variables at the individual and community level. Finally, illness and recovery are highly subjective (Bhui & Singh, 2004), and debate continues about whether religious acceptance of psychosis plays a part in reducing the rate of diagnosis of the illness (Bhugra et al., 2000; Littlewood & Lipsedge, 1981), or whether some people are mistakenly treated for a brain disease rather than a curable spiritual illness (Castillo, 2003).

Interestingly, the course of schizophrenia is significantly more benign in the developing world than in more technologically advanced countries. Themes explaining these phenomena in traditional cultures are identified as externalizing causality, thus reducing stigma and reinforcing expectations of the condition as being a temporary state, resulting in greater opportunities for social reintegration supported also by extended kinship networks (Lefley, 2000).

In Britain, a higher incidence of schizophrenia exists among the African-Caribbean population compared to the white British and the Asian populations (Al-Saffar, Borga, Wicks, Hallstrom, & Tore, 2004; Bhugra et al., 2000; Mallet, Leff, Bhugra, Pang, & Hua Zhao, 2002; Mitter, Krishman, Bell, Stewart, & Howard, 2004). However, three socio-environmental variables differentiate the African-Caribbean cases from their peers and the normal control groups: unemployment, living alone, and a long period of separation from either or both parents as a minor. In Sweden, East European, Greek, and Iranians were over-represented at a psychiatric outpatient clinic, with a corresponding under-representation of Swedish patients (Al-Saffar et al., 2004).

In a New Zealand study, Maori inmates with psychiatric disorders were found to pervade the forensic population (Brinded, Simpson, Laidlaw, Fairley, & Malcolm, 2001). There is consensus within the Canadian literature on the prevalence of psychiatric disorders among Aboriginal peoples noting that "Aboriginal communities suffer significantly higher rates of mental illness" than the general population (Canadian Standing Senate Committee on Social Affairs, Science and Technology, 2004, Article 2.2). Increasing interest in the social causation of schizophrenia

(Boydell, van Os, McKenzie, & Murray, 2004) advances the hypothesis that an impoverished social environment increases the risk of mental illness, including schizophrenia (Mallet et al., 2002), and is less a function of race than of the social, economic, and political environment that the race of people is immersed in at any given time. While experts concur that many causes of mental illness in Canadian Aboriginal peoples are similar to those of non-Aboriginals, added cultural factors are causal: "past government policies, creation of a reservation system, the change from an active to sedentary lifestyle, the impact of residential schools, racism, marginalization, and the projection of an inferior self image" (Canadian Standing Senate Committee on Social Affairs, Science and Technology, 2004, Article 2.2). Aboriginal people may be exposed to additional causal factors.

Migrant populations are more apt to have experienced traumatic events which may influence the development of psychosis and schizophrenia (Cantor-Graae, Becker-Pedersen, McNeil, & Mortensen, 2003; Lie, 2002; Sundquist, 1994; Zolkowska, Cantor-Graae, McNeil, & Mortensen, 2001). Al-Saffar et al. (2004) confirm the higher prevalence of schizophrenia in East Africans living in Sweden and argue that a weak social network when exposed to an individualist culture is a possible cause. Importantly, Black Africans are the immigrant group most often experiencing prejudice in North European countries.

While not new immigrants to the United States, African Americans in one study were found to be four times more likely than white patients to have received a diagnosis of schizophrenia (Barnes, 2004). Immigrants and visible minorities are often the most disempowered and, therefore, in a lower socioeconomic bracket. Strikingly, poverty is

considered the number one contributor to mental illness in general (Desjarlais, Eisenberg, Good, & Kleinan, 1995), although rather than poverty causing the illness, the illness may lead to lower socio-economic status (Maxmen & Ward, 1995). Religion and spirituality may also play a part in the cultural aspects of the illness (Baetz, Griffin, Bowen, & Marcoux, 2004; Stanghellini, 2005). Awareness of the implications of diversity and cultural sensitivity need to be better integrated into mental health research. Whilst the experience of racism as a cause for mental illness remains controversial (Chakraborty & McKenzie, 2002), in order to achieve successful prevalence studies and outcomes in research, future research may need to "eliminate cultural psychiatry as a separate discipline, and turn all mental health research into the study of cultures in society, within which mental health care can be positioned" (Bhui & Singh, 2004, p. 127).

2.3.2.3 Vulnerability Model

Symptoms of schizophrenia are provoked by vulnerability to stress (Leung & Chue, 2000; Rudnick, 2001). Early theoretical models of the relationship between stress and vulnerability have held their validity. As discussed earlier in this chapter, schizotaxia is a model advanced by Meehl (1962, 1989), where the interaction of genetically driven, conjectured neural integrative deficits with stressors leads to the occurrence of schizophrenia. In the diathesis-stress model, the disease exhibits a genetic tendency to interact with developmental stressors (Yank et al., 1993). The association of stressful life events with occurrences of the illness suggests that stress may provoke a vulnerability to schizophrenia (Dohrenwend & Dohrenwend, 1978). Stressors may actually trigger symptoms of disease in vulnerable populations (Rabkin, 1982), as hypothesized in the "two-hit" theory of mental illness: the first hit is genetic

predisposition, and the second hit is a stressful or traumatic life event that triggers the illness (Corcoran & Malaspina, 2004).

Canavan (2000) speculates that roles of nature and nurture can be conceptualized using a multi-locus model of schizophrenia, thus illustrating that one's genetic makeup creates a vulnerability to detrimental environmental influences. The vulnerability-stress model of schizophrenia is believed to be a result of complex interactions between genetically determined biological factors and stressful environmental factors (Cullberg, 2003; Jansen, Gispen-de Wied, & Kahn, 1999; Nuechterlein et al., 1994; Yank et al., 1993). Research bears out this theoretical supposition. The onset of psychosis is often preceded by stressful life events (Bebbington et al., 1996), such as bereavement and loss, relationship difficulties, the birth of a child, lack of sleep, alcohol and drug consumption, and isolation (Cullberg, 2003). The greater the individual's level of vulnerability, the less stress is required to trigger the psychosis (Lee et al., 2005). A selective impairment in response to psychosocial stressors in schizophrenic patients suggests the involvement of specific brain systems (Jansen et al., 1999). There may be a link between perinatal and prenatal adverse events that has an impact on a genetic predisposition to schizophrenia (Preti & Miotto, 2005). Environmental models of schizophrenia usually focus on interpersonal relationships (Beebe, 2003; Furukawa, Harai, Hirai, Kitamura, & Takahashi, 1999; King & Dixon, 1999) or adaptive processes (Provencher, Fournier, Perrault, & Vezina, 2000). Stress and coping theories are examples of environmental adaptation models. Adaptation is a dynamic process of adjusting to changeable life conditions; barriers to adaptation are addressed with coping strategies. Schizophrenia patients, with blunted cortisol responses to psychosocial stressors, have

displayed more passive and avoidant coping strategies than a control group (Jansen et al., 1999). Due to their vulnerability to stress and psychosis, patients may "react to preconscious or unconscious pressures, which have been imbued with meaning" (Cullberg, 2003, p. 213), thus further compromising their already compromised coping abilities.

These studies lend credence to the vulnerability model and may help to explain the poor coping strategies of those affected by schizophrenia and suffering from stress. Trauma may also be a factor in vulnerability to the illness.

2.3.2.4 Trauma

In keeping with the vulnerability model, a Post-Traumatic Stress Disorder (PTSD) perspective has been documented. About 90% of people with severe mental illness have experienced at least one traumatic event and most have been multiply traumatized. Trauma exposure in this population is associated with psychotic symptoms, suicidality, hostility, anxiety, and depression (Pratt et al., 2005), any one or all of which may contribute to onset or relapse of the illness. However, while PTSD symptoms are associated with greater emotional distress, PTSD is not associated with schizophrenia specific symptoms (Resnick, Bond, & Mueser, 2003). Re-experiencing symptoms of PTSD is most strongly associated with predisposition to hallucinations (Gracie et al., 2007). Another perspective of PTSD has emerged: the experience of a first psychosis and its treatment may be conceptualized as a traumatic event leading to PTSD-like problems. The patient's severe perception of threat arising from paranoia or delusions, combined with forced medications, seclusion and restraints, may be viewed as a traumatic event and non-compliance with treatment

viewed as avoidance of trauma-related stimuli (Mueser, Trumbetta, & Rosenberg, 1998).

2.4 Prevalence of the Illness

Worldwide, schizophrenia strikes 20 million people, with an annual incidence rate of 1 to 4 per every 10,000 adults aged between 15 and 24 (Davies & Drummond, 1990; Jablensky et al., 1992; US Department of Health and Human Services, 1991). However, the prevalence rate of schizophrenia is estimated at about ten times higher, with an average lifetime prevalence of 1% (Canavan, 2000; Davies & Drummond, 1990; Lee et al., 2005; US Department of Health and Human Services, 1991). Similar estimates of prevalence rates for different countries range from 2 to 10 in 1,000, while morbid risk estimates or lifetime prevalence rates are at about 1% (Beiser & Iacono, 1990). In the Netherlands, which has a population of 16 million, approximately 100,000 people have schizophrenia and more than 11,000 patients need hospital admission each year (Valmaggia, Van Der Gaag, Tarrier, Pijnenborg, & Slooff, 2005). Although Canadian-wide data is not currently available, the Epidemiologic Catchment Area of the United States reveals that the lifetime prevalence for schizophrenia ranges from 0.6% to 1.9% (Bland, 1988).

The Schizophrenia Society of Canada estimates that, per annum, 300,000 Canadians manifest the onset of symptoms of schizophrenia. Incidence and prevalence of schizophrenia varies with latitude (Saha, Chant, Welham, & McGrath, 2006) and a link between schizophrenia and winter month birth dates exists (Torrey, Bowler, Rawlings, & Terrazas, 1993). Goldner et al. (2002) find that heterogeneity in prevalence and incidence rates exist globally and urge aetiological investigation. While ongoing population surveys by Statistics Canada's Canadian Community

Health Survey (CCHS) provide new data on the prevalence of self- reported schizophrenia, survey personnel do not reach those who are homeless, in hospital, or in supervised residential settings (Public Health Agency of Canada, 2004). Prevalence data is suspected to be higher due to potential under-reporting of the disease (Swift, 2000). In contrast to most previous studies that suggest a decline in the incidence of schizophrenia, evidence of an increasing incidence of schizophrenia, and in particular for males in a Canadian cohort born between 1975-1985, has been found (Bray et al., 2006).

2.5 Gender

Onset of schizophrenia typically happens between the ages of 15 and 24, affecting men and women equally. However, a new study (3-Center AESOP Study) indicates schizophrenia is more common in men (Kirkbride et al., 2006). Major findings of the World Health Organization (WHO) studies have confirmed later onset for women. The difference between genders, on average, is between 3.5 and 6 years (Rasanen, Pakaslahti, Syvalahti, Jones, & Isohanni, 2000; Riecher-Rossler & Hafner, 2000). In fact, this difference in age of onset is probably the most consistent and robust international finding in regard to the effect of gender on clinical features of schizophrenia (Gureje & Bamidele, 1998; Leung & Chue, 2000; Takahashi et al., 2000). However, research studies from India demonstrate discrepancies from this widespread phenomenon of later onset for women (Gangadhar, Selvan, Subbakrishna, & Janakiramaiah, 2002; Murthy, Janakiramaiah, Gangadhar, & Subbakrishna, 1998; Subbakrishna, Murali, Gangadhar, & Janakiramaiah, 2001). Further, this difference in age may actually be a manifestation of a diagnostic delay due to patient gender; a schizophrenia diagnosis is given significantly more often to a male case description

than to a female one, the descriptions being otherwise identical (Hoye, Rezvy, Hansen, & Olstad, 2006, p. 1). Some of the reasons for these gender differences are now examined.

Males with the illness show poorer pre-morbid history, more negative symptoms, a higher relapse rate, a worse outcome, poorer response to neuroleptic drugs, and a lower family morbidity risk (prevalence) for schizophrenia than female patients with schizophrenia (Takahashi et al., 2000). Males require higher doses of neuroleptic medication, have more frequent and longer hospitalizations, poorer social function, require institutionalization sooner than women, and tend to have more central nervous system abnormalities than women (Rasanen et al., 2000). Women with schizophrenia and other psychotic disorders generally have better outcomes than men with similar disorders (Grossman, Harrow, Rosen, & Faull, 2006). Grossman et al. (2006) hypothesize this may be in part due to the greater social and vocational expectations placed upon men, resulting in more external stressors. As well, they surmise, substance abuse is more prevalent in males, while women may do better due to greater social skill development and they remain closer to social support systems during acute illness. Hormonal influences, such as oestrogen, may also provide a protective factor for women (Leung & Chue, 2000). Physiologically, males and females with schizophrenia demonstrate different structural and functional brain abnormalities (Takahashi et al., 2000).

These physiological differences may explain some of the difference in age of onset, although no influence of socio-economic factors can explain the differences in age of onset (Takahashi et al., 2000). Riecher-Rossler and Hafner (2000) hypothesize that as

more women marry at an earlier age than men, this may have a protective influence. However, their study does not support this hypothesis. In addition, women are more likely to have a late onset of the illness (after age 45) and display more prominent mood features than men (Public Health Agency of Canada, 2004).

In 1999, Canadian rates of hospitalization for schizophrenia in general hospitals varied with age. Men's rates increased dramatically in the 20 to 24 age group, and remained high before beginning to decrease in the 40 to 44 age group. Women's hospitalization patterns gradually peaked between ages 35 and 49, followed by a steady decline. Men's rates were higher than women's until age 50, after which women's rates surpassed those of men (Public Health Agency of Canada, 2002). When prevalence rates are studied globally, it is clear that schizophrenia is an illness of global concern.

2.6 Conclusion

Chapter Two has provided an introduction to the problem of schizophrenia from historical perspectives, along with some contextual information on the genetic, biological, and environmental formulation of aetiology. Genetic factors and gene-environment interactions contribute to over 80% of the liability for the disease, however, "no single gene variation has been consistently linked to the risk for developing the disease … and the precise nature of the genetic contribution remains obscure at this time" (Tandon, Keshavan & Nasrallah, 2008, p. 1). Also examined were the contributions of ethnicity and vulnerability. Finally, this chapter has provided information on the prevalence of the illness and how it impacts on gender. It is important to explore and examine the multi-faceted and thus complicated set of

aspects contributing to aetiology and diagnosis in order to fully study and understand the factors that contribute to insight development. However, it is also necessary to examine why we, as a society, even need to be concerned about whether a person has insight or not. Chapter Three now provides some context of the enormous social costs of the illness that include the burden of care, stigma, social behaviours, risks of suicide, legal issues, substance abuse issues, and financial concerns. These social costs provide the rationale for the importance of studying the phenomenon and for developing strategies to build insight in people with schizophrenia.

CHAPTER THREE RATIONALE FOR THE STUDY

3.1 Introduction

Chapter Three provides the rationale for the study and outlines the burden of care that has an impact not only on society but on the family as well. The stigma of the illness is examined along with the prevalence and impact of medication non-adherence, behaviours, suicide, legal issues, substance abuse, and financial concerns. Finally, this chapter makes a clear statement of the real problem to be investigated in this research.

Research must demonstrate a practical significance (Drisko, 1997). Schizophrenia has a profound impact on one's function in all aspects of life: self-care, family relationships, income, education, employment, housing, community, and social life (Public Health Agency of Canada, 2004). If insight can be developed and strengthened in people with schizophrenia, it will mitigate the impact on these variables. Therefore, there is a very practical significance to this research and hence strong rationale for the study.

3.2 Burden of Care

Globally, nearly 3% of the total burden of human disease is attributable to schizophrenia (Public Health Agency of Canada, 2004). It is difficult to obtain exact figures depicting the burden of care, as studies often measure and include differing factors when citing direct and indirect costs. However, even with these variations in measurements, studies do provide a strong sense of the global burden of care inflicted by the illness. The direct costs of schizophrenia in Western countries range between

1.6% and 2.6% of total health care expenditures, which in turn account for between 7% and 12% of the gross national product (WHO, 1996). This means £396 million in the United Kingdom and $18 billion in the United States. In the United States, people with schizophrenia consume about US $65 billion a year for direct treatment, and social and family costs (Lee et al., 2005; Schizophrenia Homepage, 2004), occupy 25% of all hospital beds, and account for 40% of all long-term care days (Nursing Economic, 1999). From 1996 to 2000, the mean length of hospital stay in the United States for schizophrenia was 12.7 days compared to depression at 7.6 days and bipolar disorder at 9.4 days (Harman, Cuffel, & Kelleher, 2004). In Canada, schizophrenia accounts for the longest average length of hospital stays, often twice as long, on average, as stays not involving mental illness (Canadian Institute for Health Information, 2005), and the rates of re-admission to hospital are "among the highest" for schizophrenia and psychotic disorders (Canadian Institute for Health Information, 2008). Schizophrenia is the most "resource intensive mental illness, accounting for one-third of all mental illness costs" (Nursing Economics, 1999, p. 141), and costs are mainly attributable to hospitalizations for the initial episodes and subsequent relapses (Thieda et al., 2003).

Beitchman, Inglis, and Schachter (1992) make a distinction between core and non-core costs. Core costs flow directly from the illness and may be either direct or indirect. Direct costs cover expenditures for hospital and nursing home care, physician and other professional services, drugs and appliances (Knapp, Mangalore, & Simon, 2004), and to support medical training and research (Beitchman et al., 1992). Globally, inpatient admission is the single largest contributor to the direct costs of treating schizophrenia (Knapp et al., 2004). Indirect costs may exceed direct costs

(Lee et al., 2005). Indirect costs reflect lost productivity due to morbidity and premature death (Knapp et al., 2004). Specifically, indirect costs result from lost employment productivity, unemployment, and permanent withdrawal from the labour force because of illness, injury, or death. Indirect costs include death resulting from mental illness and costs associated with the impact of the illness on families, caregivers, and institutions. In addition to the above costs, individual costs, such as decreased quality of life, have also been identified (Public Health Agency of Canada, 2002). Accurate statistics are difficult to determine as discrepancies exist in how publications gather statistical information. However, some sampling of costs in publications gives an overall view of the social burden of care.

In 1996, the total direct cost of schizophrenia in Canada was estimated at $2.35 billion, which was 0.3% of the Canadian gross domestic product (Knapp et al., 2004). This includes health care costs, administrative costs of income assistance plans, and incarceration costs attributable to the disease.

More recently, schizophrenia was estimated to cost Canadian taxpayers $4 billion annually in direct and indirect costs (Public Health Agency of Canada, 2004).In 1996, the direct and non-health care cost burden of schizophrenia in Canada was $1.l2 billion, with 29% of this amount going to acute hospital care, 21% to provincial psychiatric hospital care, 14% to seniors' homes, and 9% to homes for the mentally disabled (Swift, 2000). The same study demonstrated an additional $1.23 billion in lost productivity associated with morbidity and premature mortality bringing the total costs to $2.35 billion. Canadian estimates of health care resource utilization due to schizophrenia vary widely. From 1989 to 1990, schizophrenia accounted for 3.6

million hospital days in Canada, or 30.2% of hospital days for all mental disorders (Health Canada, 1993); schizophrenia accounted for the longest average length of stay of any mental illness (Canadian Institute for Health Information, 2005). Canada's financial burden of schizophrenia varied from under 1% to 3.5% of gross national product (Andrews et al., 1985; Davies & Drummond, 1990; Gunderson & Mosher, 1975).

In the United States, the hidden or indirect costs associated with schizophrenia account for US $46 billion a year in such factors as lost work time for patients and caregivers, social service costs, and criminal justice resources (Schizophrenia Homepage, 2004). In Canada, in a similar time frame, the indirect costs of schizophrenia account for $48 billion annually (Public Health Agency of Canada, 2004). The Canadian figures are larger, likely, in part, due to Canada's broader universal social support system.

3.3 Vocational Costs

Most people suffering from mental illness lack paid employment (Ruesch et al., 2004), or the illness affects their occupational performance (Janca et al., 1996). The onset of schizophrenia usually leads to disruptions in an individual's education and ability to sustain employment (Krupa, 2004; Marwaha & Johnson, 2004; Ruesch et al., 2004; Russinova et al., 2002). Schizophrenia has been "viewed as a disorder that is incompatible with a high level of vocational success" (Russinova et al., 2002, p. 304). While work, generally, is correlated with positive outcomes in social functioning, symptom levels, quality of life and self-esteem (Marwaha & Johnson, 2004), employment is a demanding social role which can provoke the underlying

psychobiological vulnerability of the individual with schizophrenia (Krupa, 2004). Hence, employment or work, in juxtaposition with the vulnerability, can stress the coping abilities of people with schizophrenia.

A report of the WHO and International Labour Organization (ILO) estimates an unemployment rate of 90% for those suffering from a serious psychiatric illness (Harnois & Gabriel, 2000). Employment rates for people with schizophrenia range from 15% to 40% (Russinova et al., 2002). European studies report employment rates of between 10% and 20% (Marwaha & Johnson, 2004). Therefore, a large percentage of the total financial burden estimates calculated to date are due to productivity losses: 65% to 92% (Davies & Drummond, 1990), 78% (Andrews et al., 1985), and 59% to 73% (Gunderson & Mosher, 1975). Globally, it has been noted that people with schizophrenia have trouble finding and keeping paid employment. Lost productivity has been attributed to patient morbidity and mortality (Knapp et al., 2004). Furthermore, exploration of the relationship between work and quality of life reveals that subjects "without any work-like occupation have the smallest social networks with comparatively few contacts to close friends, colleagues and relatives" (Ruesch et al., 2004, p. 689). Typically, as the disease strikes those in their so-called productive years, only 30% to 40% of people with schizophrenia marry and most have limited social contacts (Public Health Agency of Canada, 2004).

In 1996, the average monthly earnings for males aged 35 to 44 in the general population in Canada was $3,661, versus $2,856 for males with schizophrenia. By comparison, the average earnings for the general population of females versus females with schizophrenia aged 25 to 34 years was $2,936 and $2,221, respectively. The total

value of lost production due to morbidity for both genders in these two age groups was $391.5 million and $209.7 million, respectively. Figures may in actuality be higher than this due to the growth in inflation by 2% or 3%, increases in population, and other costs.

Very limited information is available on the number of people collecting social assistance due to a disability in Canada. The 1991 Health and Activity Limitation Survey publication (Statistics Canada, 1991) stated that 683,000 Canadians between the ages of 15 and 64 residing in households (not institutionalized) received some form of disability income. Of these, 271,100 or 39% were on provincially funded social assistance. However, this publication acknowledges that these numbers are underestimated. In Ontario, 25% of those on social assistance had psychiatric disorders. British Columbia's provincial disability system does not collect statistics distinguishing between diagnoses but some estimates can be produced. BC Stats (2005) puts the population at 4,219,918. Given the prevalence rate of 1/100 who will develop schizophrenia, we can estimate that 42,199.18 British Columbians will develop schizophrenia, and of those, using the WHO figure of 90% of people with severe mental illness who are not employed (Harnois, & Gabriel, 2000), some estimation of costs can be calculated. The current disability rate for social assistance in British Columbia is $856.42 per month. Therefore, the cost of this illness in British Columbia is $32,526,199.55 per month. In addition, these figures do not reflect the costs to private disability plans for those who have filed claims for disability benefits through their employer following functional decline caused by the illness. While lacking accuracy, these figures highlight the extent of the problem in Canada.

3.4 Family Costs of the Illness

The Handbook for Families, published by Health Canada (1990) in cooperation with the Schizophrenia Society of Canada, articulates social and practical costs faced by families of those suffering with the illness. By default, de-institutionalization of the mentally ill has often left the responsibility for their care to their families (Addington, Guebaly, Campbell, Hodgins, & Addington, 1998), usually middle-aged or older parents (Milliken, 2001), and most often the mothers (Gutierrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005). This "informal care" (Gutierrez-Maldonado et al., 2005) places a heavy burden on families (Addington, Coldham, Jones, Ko, & Addington, 2003; Knapp et al., 2004; Lukens, 2004; McDonell, Short, Berry, & Kyck, 2003). Schizophrenia causes disruptions to normal family functioning often due to the stigma attached to schizophrenia, which negatively impacts on the patient's ability to acquire housing, employment, and social support (Dickey & Azeni, 1996). In addition, families are concerned about medication non-adherence (Coldham, Addington, & Addington, 2002; Dickey & Azeni, 1996), the financial costs that accompany legal difficulties, and substance abuse by those with the illness. Finally, families frequently face the difficult decision of having their family member involuntarily committed to hospital (Crisanti, 2000).

3.5 Caregiving

As a result of their illness, people with schizophrenia have difficulty maintaining satisfactory, stable independent housing and close interpersonal relationships with people (Browne & Courney, 2005). Globally, in the 1990s, the proportion of people with schizophrenia living with relatives ranged between 40% in the United States to more than 90% in China (Xiong et al., 1994). The World Health Organization (1996)

reported that while difficult to quantify, estimates of the extent of family burden of those caring for a relative with schizophrenia range from 30% to 80% of families. A five-country European study (Foster, Melzer, Gill, & Hinds, 1996) indicated that the typical family, on average, spent six to nine hours a week providing support for their relative with schizophrenia. In the United States, the mean hours spent by family members in caregiving activities was 67 hours per month (Franks, 1990). These cultural differences in caregiving may be related to legislation, centrality of the family, availability of mental health services, stigma, and external help-seeking beliefs (Kung, 2000).

In its brochure entitled *Families Helping Families*, the Schizophrenia Society of Canada (2002) offers a sad litany of how schizophrenia affects families: sorrow, anxiety, fear, shame, guilt, isolation, bitterness, ambivalence, anger, jealousy, depression, denial, blame, pathological focus on the illness, marital discord, divorce, desire to move away, sleeplessness, weight loss, social withdrawal, search for explanations, increased substance abuse, and concern for the future. Milliken (2001) also lists powerlessness, isolation, repressed anger, fatigue, and grief. Additional costs imposed on caregivers include: household expenditures, travel costs, and lost earnings (taking time off work or stopping work altogether to care for their relative) (Knapp et al., 2004). These lists highlight the pervasiveness of the illness and its devastating effect on families. Higher levels of objective and subjective burden by caregivers are associated with high levels of expressed emotion by the caregiver, which can then increase the risk of relapse in their family member with the illness (Butzlaff & Hooley, 1998; Kavanagh, 1992).

> The typical family of a mentally ill person is often in chaos. Parents look frantically for answers that often can't be found; siblings flee. Hope turns to despair, and some families are destroyed no matter how hard they try to survive. (Schizophrenia Society of Canada, 2002, p. 11)

The British Columbia Task Force of Families of People with Mental Illness notes that 99% of respondents reported their own mental health was affected (35% severely affected) while 75% of the respondents reported effects on their physical health. Of these, 25% reported severe physical health problems (BC Ministry of Health and Ministry Responsible for Seniors, 1993). While community-based care services can reduce caregiver burden, this requires very active use of these services by the caregiver in order to experience less burden (Roick, Heider, Toumi, & Angermeyer, 2006). Caregiving to a family member with schizophrenia has significant and often negative consequences for the caregiver.

3.6 Stigma

The stigmatization of mental illness further complicates the difficulties and grief suffered by people with the illness and their families. Canavan (2000) found that half of the families of recently hospitalized schizophrenia patients concealed hospitalization, and one patient's husband blocked his wife's hospitalization in denial of her illness. Despite empirical evidence that contradicts theories such as "schizophrenogenic mother, the double bind theory, and marital skew and schism" (Canavan, 2000, p. 7), covert blame by society still falls on families and mothers of people with schizophrenia, who are often the main caregivers. This blame leads to therapeutic misalliance with the physician, which creates conflict and mistrust, contributing to poor outcomes (Canavan, 2000). In *Fourteen Principles for the Relatives*, Dr Ken Alexander gives the following advice to families: "Never become a

moth around the flame of self-blame. It can destroy your chance of coping, forever. It can destroy you" (Schizophrenia Society of Canada, 2002, p. 12).

3.7 Medication

The difficulty of predicting how an individual with schizophrenia will respond to medication is a "desperate" problem (Fleischhacker & Widschwendter, 2006) and this problem overlaps with the problem of medication non-adherence. Medication non-adherence soars as high as 70% to 80% among patients with schizophrenia (Whitty & Devitt, 2005) and is a major concern in treating people with schizophrenia (Adams & Scott, 2000; Dickey & Azeni, 1996).

Non-adhering patients tend to be younger, have shorter durations of illness, have an episodic course of illness, report side effects less frequently, make incorrect attributions to current positive symptoms more frequently, and have a more negative subjective response to medication. Interestingly, key relatives of non-adherent patients are most often employed, and, therefore, less able to provide support. Some patients refuse to take medication, due perhaps to lack of insight, unpleasant side effects, an overly complicated medication regime, or the patient's preference for the benevolent voices in his or her head. Approximately 50% of outpatients and 20% of inpatients fail to take prescribed medication (Agarwal, Sharma, Kishore Kumar, & Lowe, 1998). Forty percent stop taking their medication within the first year following diagnosis, and by the two-year mark, the rate has climbed to 75% (WHO, 1996). Tamminga (2003) dubbed antipsychotic medication as "mechanistic insight" and the phrase refers to the leverage that antipsychotic medication has over a lack of insight. Without this leverage, the lack of insight is a major factor in relapse and

hospitalization and is likely to be the most difficult problem associated with the illness (Coldham et al., 2002; Yen et al., 2005). Often, families are first to feel the brunt of the effect of their loved one's non-adherence to medication.

3.8 Behaviours

Families often find their ill loved one's behaviour to be embarrassing or bewildering. These feelings may arise from observing people with schizophrenia who look or dress "funny", talk to themselves (Barker, Lavender, & Morant, 2001), or engage in bizarre conduct, like being naked in public. They may also be hostile (Barker et al., 2001), have poor hygiene, and no longer respond to normal social cues. Family distress is often related to patients' apathy, inactivity, or failure to comply with social duties, rather than with more psychotic or behavioural symptoms (WHO, 1996). However, the burden is closely linked to the extent of symptomatic behaviours of their family member with the illness (Lowyck et al., 2004). Families are more distressed by patient disorganization rather than negative symptoms in first episode psychosis (Addington et al., 2003). Cultural differences also exist. For instance, Salleh (1994) found that 41% of Malaysian families perceived hostility, violence, and disruption of family activities as the main sources of stress.

3.9 Suicide

Suicide is another chief concern for families. Torrey (2001) estimates that 10% of all patients with schizophrenia kill themselves, most commonly in the first five years of developing the illness. Healy et al. (2006) suggest these estimates may be low given that their findings point to increasing suicide rates for patients with schizophrenia. Their review suggests de-institutionalization and use/non-use of antipsychotic

medication as possible causes for the increase in suicide rates. The lifetime mortality rate is 1.6 times greater than would be expected in the general population (Palmer, Pankratz, & Bostwich, 2005). In Canada, between 40% to 60% of people with schizophrenia attempt suicide (Mandal, 2002; Public Health Agency of Canada, 2002). Suicide attempts are one of the best indicators of the risk of committing suicide (Rascon et al., 2004). Risk factors for people with schizophrenia include: previous suicide attempts, depression, hopelessness, substance abuse, male gender, and a young age (Kaneda, 2006). In a meta-analysis on the incidence of suicide, the percentage of deaths from suicide was found to be significantly higher in males than females, but studies on suicide rates need refining to include differentiation of subtype of schizophrenia, age, inpatient versus outpatient, ethnic group, social class, education, marital status, and treatment (Lester, 2006).

The profile of the schizophrenia patient most likely to commit suicide is: young, male, white, has never married, has good pre-morbid function, has post-psychotic depression, and has a history of substance abuse and suicide attempts (Pompili, Ruberto, Kotzalidis, Girardi, & Tatarelli, 2004).. Those at highest risk "have a remitting and lapsing course" and "poor response to medication", are "socially isolated, hopeless about the future, and have a gross discrepancy between their earlier achievements and their current level of function" (Torrey, 2001, p. 124). Caregiver awareness of suicidality is an independent predictor of caregiver burden (Jones, Roth, & Jones, 1995; McDonell et al., 2003).

3.10 Legal Issues

Legal issues are a worry for families (Roesch & Golding, 1985; Teplin, 1984). Those suffering from a mental illness are more likely to be incarcerated than the general public. In fact, an estimated 5% of inmate days in Canadian jails could be attributed to schizophrenia while the crime rate for people with severe mental illness is higher than that of the general population (Swift, 2000). A Correctional Service of Canada study released in 1992 revealed that 10.4% of the federal male inmate population suffered from some form of schizophrenia (Mandal, 2002). The lifetime prevalence of psychotic disorders was found to be as high as 29.3% among inmates in security units. In alcohol and drug treatment centres, this rate was 25.3% (Mandal, 2002). Offences committed by mental patients range from shoplifting, mischief, such as wilful damage to property (Martin's Annual Criminal Code, 2004) and "dine and dash", to more serious crimes such as assault, arson, or murder (Health Canada, 1990). People with schizophrenia are more likely to be convicted of an offence involving violence (Wallace, Mullen, & Burgess, 2004).

3.11 Substance Abuse

Substance abuse escalates the family and legal costs. People with schizophrenia have an abnormally high risk of developing substance abuse disorders during the course of their lives (Brady & Sinha, 2005; Cantor-Graae, Norstrom, & McNeil, 2001; van Nimwegen, de Hann, van Beveren, van den Brink, & Linszen, 2005). Substance abuse frequently co-exists with mental illness and manifests its first symptoms in adolescence (van Nimwegen et al., 2005). Rates of substance abuse in patients with a major mental illness are estimated to be between 20% and 40% (Barrowclough et al.,

2001). As many as 60% of patients with schizophrenia use illicit drugs (Pencer & Addington, 2003). Mental health patients use 3.6 times more alcohol, 5 times more cannabis, 6.5 times more opiates, and 13 times more cocaine than the general public (Negrete, 2003). In general, the "odds" of a substance abuse disorder are 4.6 times higher among people with schizophrenia compared with the general population (Van Mastrigt, Addington, & Addington, 2004). Cannabis use at first episode is associated with poor adherence and treatment drop out (Miller, 2007). Complicating the picture is the fact that alcohol and drugs can provoke relapse of a psychotic illness. An autobiography by George Trosse in 1656, notes that an English minister believed to have schizophrenia was "so drunk on the day the illness began that he fell from his horse and had to be put to bed" (Heinrichs, 2003, p. 351). This historical evidence illustrates that even in the 17th century, it was suspected that substance abuse might provoke psychosis and/or relapse of the existing illness (Heinrichs, 2003).

Individuals with a "dual diagnosis" (those with a mental illness and who abuse substances) are more prone to engage in violent behaviour (Dickey & Azeni, 1996; Soyka, 2000). The "misuse of substances among those with psychotic disorders is associated with greater severity of symptoms and poorer prognosis, significantly more admissions to hospital and outpatient visits, higher medication dose and medication non-adherence" (Pencer & Addington, 2003, p. 49). Further complications exist: higher health care costs, trauma, suicide, child abuse and neglect, and more medical co-morbidity (Geppert & Minkoff, 2004). Dickey and Azeni (1996), in their review, highlight the strong correlation between mental illness, substance abuse, chronic homelessness, and housing instability, and conclude that nearly 20% of homeless mentally ill adults have a co-occurring substance abuse diagnosis.

Tobacco consumption is also part of the overall substance abuse picture. Psychologically, smoking relieves stress and improves concentration, while biologically, smoking may mitigate some of the positive and negative symptoms and has the potential to reduce side effects of antipsychotic medication (Forchuk et al., 2002). More than 70% of people with schizophrenia are addicted to nicotine, as compared to 27% of the general population (Action on Smoking and Health, 2001; Forchuk et al., 2002). Some studies cite rates of nicotine addiction as high as 90% (Forchuk et al., 2002; Negrete, 2003), while the DSM-IV-TR (2004) supports this estimate in their report that 80% to 90% of individuals with schizophrenia are regular cigarette smokers. Not only is the prevalence of smokers higher in this population, but people with schizophrenia consume three times the amount of cigarettes than the general population (Addington et al., 1998). In all, substance abuse continues to be a significant problem for people with schizophrenia.

3.12 Financial Concerns

Finally, money is often poorly managed by mentally ill people, and the cost of subsidization is frequently foisted upon family members. Commonly living on a disability pension, people with the illness may spend all or most of their income on impulse purchases or bestow it upon friends, family members, or strangers (Health Canada, 1990). Much of their income may be used to purchase cigarettes. Statistics on smoking consumption reveal that in 2001 the average daily cigarette consumption was 26 units (Gilmore, 2002). Hence, the daily consumption rate is 78 cigarettes for people with schizophrenia. At $7.35 (current prices in British Columbia) for a pack of 20 cigarettes, this results in daily costs of nearly $29.40 and a monthly expenditure of

$882 for tobacco alone. Costs of tobacco consumption contribute to the poverty of this population and the financial subsidization required by families. Prevalence rates may be affected by the fact that smoking has both a psychological and biological benefit to coping with the illness. Clearly, families are heavily burdened when supporting a loved one with schizophrenia yet paradoxically, the family plays a key role in stabilization of their family member with the illness (Kuipers, 2006; Rosenfarb, Bellack, Aziz, & Sayers, 2004).

3.13 Statement of Problem

Treatment for schizophrenia is severely compromised by anosognosia, or lack of insight. Anosognosia, a medical term, refers to an individual not being aware of his or her own illness and is a hallmark feature of schizophrenia. It characterizes more than 50% of all people with the illness (Schizophrenia Digest, 2004), and this lack of insight can be chronic or intermittent (Cernovsky, Landmark, Merskey, & Husni, 2004).

Aetiology of this lack of insight provokes broad debate in the literature. Psychiatric medicine and scientific research focus on questions of cause, while practitioners providing services for the mentally ill wonder whether effective interventions exist. Curiously, given the prevalence of the illness and the mental, physical, social, and economic toll of this disease, few studies have tackled the issue of how insight is developed. Sarah Chamberlain, former president of the NAMI, Vermont's state-wide Family-to-Family Education Program, observed: "Whoever figures how to get through denial and lack of insight will become a very wealthy person because this is the crux of the difficulty" (Schizophrenia Digest, 2004, p. 30). While becoming

wealthy might be of interest to some researchers, most are motivated by a more altruistic interest in the illness and a genuine desire to alleviate suffering. The objective of this research study is to reveal what factors lead to the development of insight and how people with schizophrenia themselves construct and define insight. Glimmers of "insight" into what contributes to insight may have an impact on the mental and physical welfare of people with the illness, improve and expand their psychosocial world and that of their families, and have a positive impact on the reduction of health care costs.

3.14 Conclusion

Chapter Three has provided the rationale for the study and outlined the burden of care that impacts not only on society, but on the family as well. The stigma of the illness was examined along with the prevalence and impact of medication non-adherence, behaviours, suicide, legal issues, substance abuse, and financial concerns. Finally, this chapter made a clear statement of the real problem to be investigated in this research and the practicality of solid research in this area to better understand insight development. Chapter Four now provides a full literature review on the lack of insight in schizophrenia that includes an examination of the aetiology and constructs of this phenomenon and attempts to provide some operational definitions of a lack of insight. In addition, the effects of this phenomenon upon medication adherence are discussed along with some recovery models that demonstrate this condition is not static.

CHAPTER FOUR LITERATURE REVIEW ON LACK OF INSIGHT

4.1 Introduction

Chapter Four reviews the literature on the lack of insight, more formally called anosognosia. The aetiology of the lack of insight is discussed along with an attempt to provide some operational definitions derived from the literature. Additionally, the prevalence, constructs, and effect on medication adherence are described. Finally, recovery models are highlighted to gain a perspective of the relationship between insight development and recovery.

Some qualitative researchers question the validity of conducting an early literature review. They fear that pre-conceived notions, presuppositions, and assumptions do not permit the researcher to view their subject matter with as "pure and untarnished lens as possible" (Davidson, 2003, p. 32). Conversely, a full literature review is viewed as not only valuable but crucial to "identify the predominant notions that both delimit … and limit our understanding of psychosis, giving us a springboard from which to leap into the experiential waters described by participants in our studies" (p. 36). In this case, it was necessary to conduct a literature review to determine what is known about insight development, what central questions need to be asked or considered, and/or what yet remains unknown. Therefore, this researcher plunged into the experiential waters of how insight is developed for people with schizophrenia by conducting a full literature review on anosognosia or the lack of insight.

Systematic preliminary reviews took place using MEDLINE, CINAHL, Psychological and Behavioural Science Collection, ProQuest Social Science Journals, PsychINFO, Science Direct, PsychARTICLES, Web of Science, Health Business Full Text, and Nursing and Allied Health Care Collections. In addition, the researcher utilized referencing from collected journals. Books were obtained through the Interior Health Authority Royal Inland Hospital Medical Library, the Thompson Rivers University Library in Kamloops, British Columbia, and the University of Canterbury Library in New Zealand. Standardized procedures for literature reviews were used to ensure rigor in the literature review (Goldner & Hsu, 2001). Alerts were generated for new articles in this subject area and the researcher tenaciously searched for any new and relevant literature along the course of the study period.

4.2 Aetiology and Constructs of a Lack of Insight

Many people with schizophrenia do not or cannot accept the reality that they are ill. For many years, physicians have accused patients of stubbornness, belligerence (Forsyth, 2002), and deliberate sabotage of illness interventions. However, this lack of awareness, or lack of insight, may be physiological (Amador & Paul-Odouard, 2000); the disease may actually alter the brain sufficiently to disallow insight. Individuals in denial have difficulty "recognizing and/or accepting the existence, nature, degree, and/or impact of their condition" (Kortte & Wegener, 2004, p. 187). Dr Frederick Frese, of the National Alliance for the Mentally Ill in the United States, highlights the dilemma of the patient: "Why would anyone want to be cured of an illness they don't believe they have?" (Forsyth, 2002, p. 17).

Theoretical conceptualizations of lack of insight aetiology are generally two-fold: organic/biological dysfunction (Arduini et al., 2003; Gordon, 1997; Lele & Joglekar, 1998), and the conceptualization or supposition of denial (Arduini et al., 2003). However, Boker (1999) believes three causes exist for a lack of insight: psychotic reality distortion, psychotic resistance (denial), and the expression of neurobiological deficits (anosognosia).

The degree of insight is directly correlated with the severity of neuropsychological dysfunction in the frontal lobes (American Psychiatric Association, 2001; Cuesta & Peralta, 1994; Kemp, Hayward, Applewaite, Everitt, & David, 1996; Keshavan et al., 2004; Lysaker, Bell, Milstein, Bryson, & Beam-Goulet, 1994; Woo & Crowell, 2005; Young, Davila, & Sher, 1993). This neurological impairment is hypothesized to be analogous to the unawareness of illness present in neurological disorders such as stroke and dementias (Schwartz, 1998; Verhey, Rozendaal, Ponds, & Jolles, 1993; Vuilleumier, 2004). Frontal symptoms do not necessarily imply the presence of a frontal lesion, but instead may be a common consequence of a global cerebral impairment (Arduini et al., 2003). Smaller prefrontal grey matter volume is associated with poor insight in stable patients with schizophrenia (Sapara et al., 2007).

The lack of insight in schizophrenia is related to poor executive function (Lysaker, Bryson, Lancaster, Evans, & Bell, 2002), and, perhaps more generally, to cognitive deficits (Donohue, Corvin, & Robertson, 2005). However, Koren et al. (2004) report that the relationship between neuropsychological function and executive function is simplistic and suggest that some study designs do not account for metacognitive levels of function due to such factors as over-reliance on standardized forced

responding tasks that do not allow patients the freedom to decide whether to volunteer or withhold answers. This relates to the insight behaviours of self-monitoring and self-direction. Koren et al. (2004) speculate that free choice performance accuracy, which depends on metacognitive skills of monitoring and control, is an important mediator between basic-level cognitive skills and insight. It is not yet fully understood if lacking good insight is a measure of illness severity or whether it is an acquired construct (Sevy, Nathanson, Visweswaraiah, & Amador, 2004).

Symptom severity may actually play a greater role in unawareness than cognition (Donohue et al., 2005). A relationship between overconfidence in judgements and impaired self-reflectiveness in patients with acute psychosis is suggestive of some cognitive impairment (Bora, Erkan, Kayahan, & Veznedaroglu, 2007). Mysore et al. (2007) further this conceptualization and separate the difference between unawareness of illness and misattribution of the symptoms. Insight may be related to capacities to shift attention between differing environmental demands, plan ahead, and construct contextual understandings (Lysaker, Whitney, & Davis, 2006).

Initially, lack of insight was thought to be a psychological defence or response to an illness called denial (Arduini et al., 2003; McGorry & McConville, 1999). Denial, then, is a mechanism of preserving the individual's self-esteem, minimizing the disability, and preventing social stigmatization (Birchwood, Mason, & McMillan, 1993; McGlashan, Levy, & Carpenter, 1979; Mechanic, McAlpine, Rosenfield, & Davis, 1994; Warner, Taylor, Powers, & Hyman, 1989; White, Bebbington, Pearson, Johnson, & Ellis, 2000). Guardedness and psychological suppression assist in presenting oneself in a desirable light and social acquiescence (Subotnik et al., 2004).

Denial is the psychological defence mechanism called "rigid defences" (Forsyth, 2002, p. 19). Epidemiologists continue to inspect theories of denial. White et al. (2000) hypothesize that denial is affected by the social and cultural contexts of each individual but have uncovered no evidence to support their hypothesis. In fact, they conclude that psychosis is an illness that "largely transcends social and cultural boundaries" (p. 505).

In a meta-analysis of insight, Mintz, Dobson, and Romney (2003) argue that the possibility that lack of insight functions as a coping strategy "cannot be ruled out at this time" (p. 84). Denial in itself may also be an adaptive strategy (Stephenson, 2004). A modest correlation between anxiety and insight exists, but it is not clear if individuals understand they are having a psychotic episode or if experiencing anxiety makes them more likely to realize they are sick (Freudenreich, Deckersbach, & Goff, 2004). Seedat, Fritelli, Oosthuizen, Emsley, and Stein (2007) found that fewer than 25% of untreated schizophrenia patients met the criteria for anxiety.

Curiously, the literature does not furnish us with answers about how a person with schizophrenia conceptualizes insight; identification of this gap impels its exploration within this study.

4.3 Definitions

Expressions such as anosognosia, denial, lack of insight, and unawareness are constructs used almost interchangeably to describe the lack of insight associated with illness. Lack of insight (unawareness or anosognosia) can be found in other illnesses such as acquired brain injury, and spinal cord injury while denial can be found in

other illnesses such as heart disease, diabetes, cancer (Kortte & Wegener, 2004), but in schizophrenia, unawareness is almost a universal symptom (Schwartz, 1998; White et al., 2000). Kortte and Wegener (2004) have produced an excellent paper clearly defining and differentiating the terminology useful for a discussion of this problem. Their definitions are used for the purpose of this research: *Unawareness* indicates reduced or limited insight into the illness and refers to a class of syndromes that includes both neurological and psychological subtypes. *Anosognosia* is the subtype that refers to an individual's unawareness of his or her illness and is generally presumed to be related to an underlying neurological dysfunction. *Denial* is the subtype reserved for referencing unawareness presumed to be psychological in nature. This denial is more commonly referred to as "lack of insight" or "poor insight". Insight is defined as: perceptiveness: the ability to see clearly and intuitively into the nature of a complex person, situation, or subject; a clear perception of something; the ability of somebody to understand and find solutions to his or her personal problems; the perception that hallucinations are not real (Encarta, 2007). Goldbeck (1997) conceptualizes patients with denial or anosognosia of physical illness as people who: "(1) do not accept their diagnosis or appear oblivious to it; (2) minimize the implications of their illness; (3) delay seeking medical advice; (4) refuse or comply poorly with treatment; or (5) appear unperturbed and detached in the face of their illness" (p. 575). Anosognosia affects patients who "appear unable to notice and acknowledge the existence of their deficits, often despite blatant evidence for their handicap" (Vuilleumier, 2004, p. 9).

Amador and Gorman (1998) tend to use the words "insight" and "awareness" interchangeably and have identified factors involved in the lack of insight: the lack of

awareness of having an illness; faulty attributions, or lack of understanding that the signs and symptoms or consequences of the disorder are related to mental dysfunction; ignorance of the consequences of the disorder; and lack of agreement with health professionals that treatment is needed. Rickelman (2004) notes a difference between current insight and retrospective insight (whether a patient believes she or he is sick now or has been sick in the past). A psychotic patient's capacity for insight is diminished by four components: the impairment of objectivity about cognitive distortions, the loss of ability to put these into perspective, the resistance to corrective information from others, and the overconfidence in conclusions (Beck, Baruch, Balter, Steer, & Warman, 2004).

In psychoanalysis, insight is used to signify one's "understanding of the dynamic factors contributing to conflict resolution.... (which) require(s) a degree of freedom of association, self-observation, contemplation and discernment...." (Moore and Fine, 1990, p. 90). This definition clearly defines what insight *is* rather than what *it is not.*

While a precise definition and assessment of insight is a necessary precondition for conclusive insight research, very few studies were originally designed to study insight; and there has been a lack of precision in terms of identifying the specific aspect of insight being studied and a lack of methodological rigor (Lincoln, Lullman, & Rief, 2007). However, the most often used instruments approach insight as a continuous process, rather than an all or nothing construct (Dantas & Banzato, 2007, p. 263). Cole (2008) argues for improved diagnostic classifications for insight that include the following specifiers: 1) schizophrenia with preserved insight; 2) schizophrenia with impaired insight, predominately neuropsychological features; 3)

schizophrenia with impaired insight, predominately emotional features; and 4) schizophrenia with impaired insight, mixed neuropsychological and emotional features. Cole asserts these additional specifiers will also improve the validity of predictions regarding diagnosis and treatment response.

4.4 Prevalence of Anosognosia

The World Health Organization's (WHO) International Pilot Study of Schizophrenia in different cultures found that over 90% of subjects with schizophrenia manifested poor insight (White et al., 2000; WHO, 1973). In another study, between 50% and 80% of patients diagnosed with schizophrenia were shown to be partially or totally lacking insight into their mental disorder (Lincoln, Lullman, and Reif, 2007). The prevalence of poor insight is more severe and pervasive in this population than in patients with schizoaffective or major depressive disorders, with or without psychosis (Amador et al., 1994). Rickelman (2004) found that almost 60% of people diagnosed with schizophrenia had moderate to severe lack of awareness of their mental disorder, while 27% of subjects with schizoaffective disorder and 57% of patients with manic depression were "severely unaware of specific symptoms such as delusions, thought disorder, disordered speech, restricted affect, anhedonia, asociality, and other illness manifestations" (p. 228). Levels of insight following the first psychotic episode may have implications for outcomes (Saeedi, Addington, & Addington, 2007). Manifestations of people with poor insight are closely associated with the person's competence to constitute a free will (Habermeyer & Hoff, 2004). Cernovsky, Landmark, Merskey, and Husni (2004) found that of the 111 schizophrenic patients studied, 97.3% had had poor insight at some time in the past and 58.6% had poor insight at the time of assessment. In a literature review of 39 articles regarding

medication compliance and schizophrenia, poor insight was the factor consistently associated with non-adherence with medication (Lacro, Dunn, Dolder, Leckband, & Jeste, 2002). Further, aspects of insight such as treatment compliance and recognition of illness are negatively associated with negative symptoms (Nakano, Terao, Iwata, Hasako, & Nakamura, 2004).

4.5 Effect on Medication Adherence

Lack of insight "predisposes the individual to non-adherence with treatment and has been found to be predictive of higher relapse rates, increased number of involuntary hospital admissions, poorer psychosocial functioning, and a poorer course of illness" (DSM-IV-TR, 2004, p. 304). Numerous research studies confirm a positive correlation between insight and compliance with treatment, which can lead to successful treatment outcomes (Lacro et al., 2002; Lysaker et al., 1994). Three separate but overlapping dimensions of insight are described: treatment adherence, awareness of illness, and ability to re-label the psychotic experience correctly (David, 1990).

Conflict exists between researchers around whether the lack of insight has relevance to psychosocial adjustment. One study finds no bearing on psychosocial adjustment (Simon, Berger, Giacomini, Ferrero, & Mohr, 2004), but another shows poor insight negatively affects psychosocial functioning which leads to medication non-adherence (Amador & Strauss, 1994). Medication non-adherence is the biggest factor in precipitating relapse for people suffering from a major mental illness (Lacro et al., 2002; Schizophrenia Digest, 2004); and non-adherence rates are as high as 89% (Lacro et al., 2002). Early insight predicts a lesser likelihood of future relapse by

promoting medication adherence (Heinrichs, Cohen, & Carpenter, 1985; Kent & Yellowlees, 1994). Increasing insight, as an early intervention strategy, is an important attribute of successful treatment (Schwartz, 1998). This conclusion is largely consistent across the literature. In addition, poor insight limits psychotherapeutic treatment effectiveness and reduces treatment outcomes (Amador & Strauss, 1994). Good insight in patients correlates with superior post-hospital adjustment, positive post-discharge outcomes, drug response and drug compliance in after-care (Schwartz, 1998). Lack of insight "of being ill is not a ubiquitous, consistent, constant, or essential aspect of that illness" (Cernosvsky et al., 2004, p. 825). Therefore, if it fluctuates, perhaps it can also be influenced. Recovery models exist that demonstrate processes in insight development and provide clues as to what can influence the process.

4.6 Recovery Models

Recovery models typically have four key processes: finding hope, re-establishment of identity, finding meaning in life, and taking responsibility for recovery (Andresen, Oades, & Cuputi, 2003). Roe and Chopra's (2003) recovery domains include: the acquisition of an internal sense of meaning and purpose; a re-engagement in life; the development of social engagement; the ability to self-regulate activity; cognitive improvement; and the reversal of decompensation. Recovery is an active sense of self, a determination to get better and manage the illness, and the realization of a need to help him or herself (Tooth, Kalyanasundaram, Glover, & Momenzadah, 2003). Most recovery models emphasize a process that takes the person from being overwhelmed, to finding skills and moving beyond the illness (Chadwick, 1997; Davidson et al., 2005; Frese, 1998; Geanellos, 2005; Noordsy et al., 2002; Spaniol, Wewiorski,

Gagne, & Anthony, 2002; Thornhill et al., 2004). Forchuk, Jewell, Tweedell, and Steinnagel (2003) support a bio-psycho-social-spiritual model of managing psychosis toward recovery.

Clearly, growth and change are the result of a person's recovery experience with the illness (Roe & Chopra, 2003). Therefore, a narrative self-presentation in schizophrenia gains "complexity and dynamism" (Lysaker, Lancaster, & Lysaker, 2003, p. 285), depending on internal and external influences. Asking questions and using subjective experience as data can advance our understanding of client insight into illness recovery. Such an approach further acknowledges that environmental influences may be significant in shaping the individual's subjective experience of schizophrenia (Marley, 1998). This change in thinking reflects a shift away from practitioner scepticism of personal stories and rationalizations to a perspective where personal accounts are the "essential route to knowing and appreciating the person" (Saleebey, 1996, p. 298).

Most recovery literature comes from the United States where the vision of recovery is more individualistic and mono-cultural than in New Zealand. The *Mental Health Commission's Blueprint for Mental Health Services in New Zealand* (as cited in O'Hagan, 2001) has developed recovery-based competencies for mental health professionals to reflect their stronger tradition of state provision for the vulnerable and marginalized. There are similarities in New Zealand and Canada's socio-economic strengths and weaknesses (Canadian Council on Social Development, 2005, p. 7). Canada is committed to "the critical importance of social programs in creating healthy communities and ensuring the wellbeing of all Canadians" (Canadian Council on

Social Development, 2005, p. 2). Canada is, in fact, closely watching New Zealand's experience in renovating social programs. Canada emphasizes the biopsychosocial approach, such as the Community and Knowledge Resource based models and the Effort Spectrum model, that focuses on recovery and resilience (Public Health Agency of Canada, 2004).

Regardless of ideology, recovery can be defined as the ability to live well in the presence or absence of one's mental illness (O'Hagan, 2001). To that end, this qualitative research aspires to identify the conditions, factors, and processes that foster the awareness of and acknowledgement of schizophrenia and its symptoms by giving "voice and strength" to the consumer of mental health services. This research also aspires to unearth how and when people with schizophrenia conceptualize and define insight and then engage in recovery processes.

4.7 Conclusion

Chapter Four has reviewed the literature on the lack of insight, more formally called anosognosia. Greater understanding of the concept of lack of insight is necessary in order to be familiar with the complex and multi-faceted theoretical models of a lack of insight aetiology. The constructs of the lack of insight were discussed along with some attempt to provide operational definitions derived from the literature that assist with some common understanding of the concepts developed to date. Additionally, very high prevalence rates of the lack of insight and the effect this lack of insight has on medication adherence rates make this illness a global concern. Finally, this chapter discussed some recovery models that have been developed and that may have an impact on perspectives of the recovery process and outcomes of the illness. Chapter Five now provides the theoretical perspectives on care for people with schizophrenia

that include ideological, historical, social, and psychological contexts. This chapter also discusses the Health Belief Model and concludes with a discussion about the rights of a person suffering from schizophrenia.

CHAPTER FIVE THEORETICAL PERSPECTIVES ON CARE

5.1 Introduction

Theoretical perspectives of care for people with schizophrenia are influenced by a multitude of factors. Chapter Five outlines the theoretical, ideological, historical, social, and psychological perspectives on care for schizophrenia. It discusses the Health Belief Model of care and examines how the rights of the individual with schizophrenia are considered across international contexts. Finally, issues of consumerism and self-determination are discussed. Familiarization with these concepts provides a background to understanding perspectives of care directed at people with schizophrenia. As demonstrated later in the thesis, this current research influences these perspectives on care for people with schizophrenia.

5.2 Ideological and Historical Context

Foucault provides an ideological and essentially ecological perspective along with some historical context demonstrating that mental illness is both socially constructed and linked to the environment in which people live. People with mental illness may be physiologically and genetically "hard-wired" to be predisposed to the illness, but are also affected by the social environment they live in and how the illness is viewed by society. In 1700 France, the Comte de Mirabeau was a prominent political figure, who, imprisoned for periods of time due to excess in lifestyle, noted that "madness was in large part an outcome of confinement itself" (Boyne, 1990, p. 12). Thus, madness can, in part, be constructed by the environment or the social milieu in which a person lives.

Social construction determines what is defined by mental illness. When behaviour is viewed by the wider society as other, different, deviant, pathological, concerning, and dangerous, the behaviour is often labelled mental illness and this has an alienating and stigmatizing impact upon the individual. This same behaviour in a different culture may be considered gifted and, therefore, valued in the society. Foucault challenges us to "grasp a form of human existence entirely other than our own … a right to be different" (Boyne, 1990, pp. 32-33). His belief is that "otherness" is innate in humans and can only be repressed, not extinguished. Behaviour, therefore, continues to be influenced by the construction placed upon it by society.

Social control mandated by society is a result of society fearing the "otherness" in mental illness. Foucault believed this otherness of the mentally ill was created through their unproductivity. "The insane would find their home in these places apart, not because they were ill, but because they were unproductive" (Boyne, 1990, p. 5). These "moral deviants" who were unable to work were placed into institutions; they were of no use to the ruling class.

Historically, the mentally ill suffered from practices of "exclusion, of casting out, of marginalization" (Foucault, Marchetti, Burchell, & Salomoni, 1999, p. 43). This exclusionary form of social control did little to "normalize" the deviant behaviours. Yet another model of social control appears to have enjoyed greater success, that of restoring and maximizing health, longevity, and strength of the individual (Foucault et al., 1999); a restoring of the norm. As Foucault et al. explain: "The norm's function is

not to exclude and reject. Rather, it is always linked to a positive technique of intervention and transformation, to a sort of normative project" (p. 50).

Foucault broke with Marxist structuralism and the "Marxist emphasis on class struggle and the state as the foci of power" (Layder, 2006, p. 126). Foucault believes humans are not inherently free, but rather corralled by social determinants that prevent their freedom; a more "capillary" like structure of distributed power. Power, Foucault believes, is everywhere and operates "within people through internalized disciplines and normalized identities, routines and practices" (p. 130). Thus, the power given to professional domains, such as psychiatry, medicine, social work, and other disciplines contributes to this power everywhere. With this power comes domination. People are not free; the socially constructed determinants and dominants of the society in which they lived empowered some and devalued others (p. 120). Despite moving away from structuralist thinking, Foucault maintains a structural remnant by centring his "analysis at the level of objectivity and to steer away from the error of subjectivism" (p. 117). He disagrees with humanist thinking that through the human consciousness, the individual creates their own meaning through their encounters with their social world. Yes, people live their lives through socially constructed meanings available to them, but, as he points out, individuals do not create these meanings or the practices they inform. Foucault de-centres the individual as the "source of meaning and as the building block of social analysis" (p. 118).

A poststructuralist, postmodern viewpoint acknowledges that the complexity of individuals, their beliefs, values, and drives create tensions within themselves and within their relationships that are as individual as they are common. How individuals

make meaning of their lives is "produced through intersubjective processes of negotiation, definition and general forms of creativity that are brought into play whenever and wherever human beings mix socially" (Layder, 2006, p. 135). The problem with interactive perspectives is that they "tend to view meaning solely as emergent from face-to-face situations and, as a consequence, overlook the socially constructed production of meaning" (p. 135). Foucault's work is important as it points out that power is in-situ in the environment or society at large and not necessarily a governmental "power over" in our society. He moves social analysis forward, by de-centring the individual and recognizing that the individual's construction of meaning in their lives is not independent of social constructs. An environmental influence dominates. However, Foucault does not seem to find a way to overcome the paradox inherent in holding at once to a view that structure is dominant in shaping individual views, and that the intersubjective meaning making is powerful in subverting that dominance. "He still retains the idea that people are conditioned by social discourse and practices but now the individual is seen as a creative agent who can overcome socially imposed limitations and attain self mastery"(Layder, 2006, p. 125).

The importance Foucault placed on the historical and social construction of illness had potential to detract from the hope that progress in physiological knowledge was the panacea for mental illness (Bernauer, 1990). However, growing knowledge in neuropsychology and genetics is moving the other way, to re-focus on science to solve the riddle of mental illness: "knowledge caused madness to be perceived as pathology, as a problem to be overcome and even entirely banished from the human realm" (Boyne, 1990, p. 29).

5.3 Social Context

Shifts in ideological thinking in the 1970s to 1980s brought about the de-institutionalization of the mentally ill. This deinstutionalization has produced "unintended consequences" as people with mental illness become homeless, criminalized, and now present challenges to society (Lamb & Bachrach, 2001, p. 1039). With these ideological shifts and the unintended consequences, society's fear of the dangerousness of these "abnormals" and "deviants" has risen.

Dangerousness is also a social construction. The dichotomies between crime and responsibility have long been debated between the medical and legal system. Which is it? Is the person mad and, therefore, not responsible, or is the person criminal and therefore responsible and punishable? Foucault et al. (1999) believe:

> One must choose, because madness wipes out the crime. Madness cannot be crime, just as crime cannot be, in itself, an act rooted in madness. It is the principle of the revolving door: In terms of the law, when pathology comes in, criminality must go out. In the event of madness, the medical institution must take over from the judicial institution. Justice cannot take possession of the mad, or rather, when it recognizes someone as mad, justice must relinquish jurisdiction and release him or her. (pp. 31-32)

Judges relinquish social control of the "mad" to psychiatrists who become the new agent of social control over these "abnormal" individuals. It is their job to "to detect danger and counter it" (Foucault et al., 1999, p. 35). The psychiatrist has to "comment on the connections between madness or the illness and the possibility of disturbance, disorder, and danger … the sources of danger at the level of behaviour" (p. 141). This authority is given to physicians through mental health acts; legislation to institutionalize a person assessed as dangerous to self or others, placing physicians in positions as "sentinels rather than as kindly and concerned humanitarians" (Boyne, 1990, p. 13).

Poletiek (2002) studied how judges and psychiatrists define dangerousness and found that judges deem dangerousness more often as harm to others, thereby protecting society by depriving liberty, while psychiatrists, more often, base their decisions on harm to self, thereby focusing on the "opportunity to be treated". Poletiek referred to these differences as "expertise bias" (p. 28).

5.4 Psychological Context

In addition, psychiatrists are hampered by the medical setting and, hence, some are not able to evaluate the person's contextual, political, cultural, statistical and informational domains (Levinson & Ramsay, 1979). Contextually, assessments undertaken in medical settings remove the social and environmental context within which the patient dwells, and the psychiatrist may not know the cultural and socio-economic status of the patient. Statistically, it is very difficult to predict dangerousness, and yet society demands the psychiatrist make these judgements perhaps without knowing the personality or how that personality interacts with the environment.

Foucault's inability to resolve the paradox between social construction and intersubjective meaning making continues. Dangerousness to self and others is currently defined by society, which does not take into consideration the intersubjective meaning making of what constitutes dangerousness by the individual with the illness. The Health Belief Model of care focuses on how the patient's beliefs about the illness affect adherence to treatment.

5.5 Health Belief Model

The Health Belief Model tenders a perspective for understanding how a patient's beliefs and attitudes can affect his or her adherence to treatment (Kelly, Mamon, & Scott, 1987; Lacro et al., 2002; University of South Florida, 2005). The premise of the model is that a person's perception of the world predicts what he or she will or will not do. The original Health Belief Model schema (Rosenstock, 1974) contains five factors that affect adherence:

1. *Perceived susceptibility*: This refers to a person's subjective beliefs of contracting a given condition. At one extreme, the person is denying any possibility of contracting a given condition, while a more moderate position is the person admitting to a "statistical" probability of a disease occurring, but not likely to happen. At a more extreme end, the person is expressing a feeling of real danger of contracting the condition;
2. *Perceived seriousness*: This refers to the belief a person holds concerning the effects of a disease and the difficulties the condition may create "on his job, on his family life, and on his social relations … its occurrence would be serious if it created important psychological and economic tensions within his family" (p. 331). Perceived susceptibility and severity have strong cognitive components that are at least partly dependent on knowledge;
3. *Perceived benefits of taking action*: Taking action refers to the beliefs regarding the effectiveness of treatment in reducing disease threat and how beneficial this treatment would be in his or her case. If the person believes that he or she has no illness, there are no benefits to treatment compliance. Conversely, if they believe that their illness is serious, they may have a strong conviction "that there are no efficacious methods of prevention and/or control" (p. 331);

4. *Barriers to taking action:* The concept of "barriers to taking action" refers to the belief the person holds about the "inconvenience, expense, unpleasantness, painful or upsetting" nature of the treatment (p. 331);
5. *Cues to action*: This refers to recognition and response to the cues offered by an illness to take action. The cues to action are "internal (for example, perception of bodily states) or external (for example, interpersonal interactions, the impact of media of communication, or receiving a postcard from the dentist" (p. 332). The intensity of the cue deemed sufficient to trigger action is "presumably varied with differences in the levels of susceptibility and severity" (p. 333).

There may be some utility in using this Health Belief Model in psychiatric research (Adams & Scott, 2000). However, insight into illness and health beliefs are independent of one another. Both are separate clinical phenomena and both influence health behaviours in patients, most notably, cooperativeness with treatment or treatment attrition (Linden & Godemann, 2007). Patients' ways of understanding mental illness *do not* parallel those described in physical illness. The beliefs they assign to their difficulties do not entail appraisal of an "exogenous illness entity" (Kinderman, Setza, Lobban, & Salmon, 2006, p. 1908) but rather "episodes of irrationality" (p. 1909). The Health Belief Model continues to be a tool for physical rather than mental health care analysis. However, it appears that it can be applied to all chronic illnesses, including schizophrenia due to these episodes of "irrationality".

Given what we know about anosognosia, it is clear that an individual's lack of insight negatively affects the factors that direct adherence. In fact, Rusch and Corrigan's (2002) aspects of insight neatly align with the health belief model:

1. *The cognitive aspect*: This refers to the awareness of mental illness, acceptance of illness, and awareness of social consequences;
2. *Compliance related aspects*: This is the "perception of the need for treatment, awareness of effects of treatment, attribution of possible benefits to treatment, and cooperation with treatment" (p. 24);
3. *Symptom related aspects*: This is the "awareness of individual symptoms and attribution of symptoms to the disorder" (p. 24);
4. *Temporal aspects*: This relates to the degree of insight into having the disorder, degree of insight into having had the illness in the past and the past need for treatment, and having the illness and needing treatment in the future.

If there is no insight, "the perceived costs outweigh the perceived benefit" and "non-adherence becomes much more likely" (Lacro et al., 2002, p. 893). Therefore, development of insight helps mitigate the resistance to treatment compliance, is an indicator of prognosis, and is likely to reduce readmission rates (Buchanan, 1992; Cuesta, Peralta, & Zarzuela, 2000; Kemp et al., 1996). However, the Health Belief Model includes self-efficacy, or the perceived ability to successfully initiate the given response (Zak-Place & Stern, 2003). Therefore, even when the perceived benefits of the treatment outweigh the perceived costs of the illness, if self-efficacy is not present, non-adherence may follow. This study explores the concepts of insight and self-efficacy. It gives rise to questions such as: What if insight does not exist for some people? For the good of society, do we treat them? Revisiting classic writings in political philosophy can help expose social values on these questions concerning individual liberty and rights.

5.6 Rights

John Stuart Mill (1859/2002), in his classic dissertation *On Liberty*, declared that in order to obtain liberty in a society, one must be free of the influence of others. However, he places restrictions on this freedom. Firstly, liberty is restricted to prevent the stronger members of society preying on the weaker members of the community. Therefore, the rights of one individual are restricted to ensure the protection of another individual. Secondly, Mill limits the rights of an individual who is, for some reason, incapable, since he or she cannot know how to make the right choice. He contends that others in society, who know and understand what a human craves, can choose for these disadvantaged individuals. Their choice is based on what they believe the disadvantaged person would choose for themselves, if he or she were well. Who in modern society has the right to decide? As Szasz (1997) states:

> It's a matter of determining who has control over one's body - the State or the individual. It is enough to acknowledge who defines what and controls whom. For example, in the typical case of bodily illness, say myocardial infarction, the subject identifies him as suffering from an illness and so does his physician; whereas the typical case of mental illness, say schizophrenia, the psychiatrist identifies the subject as ill, but the subject does not identify himself as ill. (p. 21)

Therein lies the dilemma for the state, the hospital, and the physician: a patient is symptomatic, but is either not convinced of these symptoms, cannot relate the symptoms to the mental illness, or does not want to be treated. Who decides if treatment is applied? Article 18.3 of the United Nations International Covenant on Civil and Political Rights (ICCPR) states that "freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health, or moral or the fundamental rights and freedoms of others" (as cited in Gosden, 1997, p. 6). As symptoms of

schizophrenia are delusions, hallucinations, and thought disorders, do we impede patients' freedom based on their socially unacceptable thoughts and beliefs?

Article 2 of the ICCPR specifies rights for all individuals "without exception", thus limiting state power with regards to the mentally ill (Gosden, 1997, p. 7). However, our society relies on social organization, social norms, and commonly held beliefs; collective needs circumscribe individual needs. Do we treat the mentally ill, given the effects of their substance abuse, crime, family devastation, and bizarre behaviours when untreated? Mill (1859/2002) believes that we treat the "mentally crippled" in our society with a proviso:

> … that the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant. (p. 7)

Therefore, "for their own good" is not sufficient warrant for committal. Although there are clinically significant differences among provincial mental health acts in Canada (Gray & O'Reilly, 2001), the British Columbia Mental Health Act (1996), Section 22.3c (ii), states that a mentally ill patient "requires care, supervision and control in or through a designated facility to prevent the person's or patients substantial mental or physical deterioration or for the protection of the person or patient or the protection of others." Therefore, in British Columbia, we not only protect others from harm caused by the mentally ill but also protect those with mental illness from harming themselves and from mental or physical deterioration. This directly conflicts with Mill's proviso. The Canada Health Act (1984) overrides Mill's proviso by stating:

> It is hereby declared that the primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers. (Chapter 6, Section 3)

This Act delineates the rights of the state to protect, promote, and restore the mental well-being of citizen with schizophrenia, and places obligation on psychiatrists and mental health professionals to carry out these policies. Therefore, Canadians with mental illness who are a threat to self or others can be committed to a mental institution under respective provincial Mental Health Acts and forced to accept treatment. However, provincial legislation allows for a review panel hearing and appeal of the committal by the person committed (CMHA, 2004).

Britain's Mental Health Act (1983) places emphasis on consideration of the patient's health as well as their safety. Many other countries have followed this convention. In their attempts to clarify criteria and procedures, "some have turned to stricter, dangerousness criteria than those used in English statute" (Marriott, Audini, Lelliott, Webb, & Duffett, 2001, p. 38). In the United States, from 1964 to 1979, every state altered the criteria for involuntary committal, limiting it to dangerous to self or others, which included being unable to meet their basic needs. Austria, Australia, Belgium, Germany, Israel, the Netherlands, Northern Ireland, Russia, Taiwan, and Canada followed suit and adopted dangerousness-based commitment criteria with some unique departures from the American model (Appelbaum, 1997). For example, the New South Wales criteria included the "risk of financial harm, but only for those who are manic … seeking to prevent families of manic patients from being left destitute by patient's spending sprees" (Marriott et al., p. 137).

5.6.1 International Models of Rights

Some startling statistics exist related to gaps in human rights protection for the mentally ill. Approximately 41% of countries do not have a mental health policy and 25% of countries have no legislation on mental health (WHO, 2002). In response to these gaps, *WHO Resource Book on Human Rights and Legislation* (WHO, 2005), outlines the work yet to be done to standardize care across the world through effective value and evidence-based mental health legislation, policy, and regulations that drive attitudes and service delivery (WHO, 2003). Custodial care is still a reality for many people suffering from schizophrenia and judged as the best context for service delivery to people with schizophrenia (Santos, Henggeler, Burns, Arana, & Meisler, 1995).

Rights and liberties become moot if a person is aware he or she is sick and seeks treatment. If the person seeks treatment on a voluntary basis due to insight into the pathological nature of his or her condition, the state needs to neither enforce care nor do families and physicians need to make the difficult choice to commit as "forcing" the patient to accept his or her diagnosis. Forcing people to accept the label of schizophrenia may be tantamount to "acts of cruelty" (Roe & Kravetz, 2003, p. 417) given the stigma of mental illness. There may be better ways to "foster the beneficial aspects of being aware of and acknowledging a psychiatric disability without our incurring the risk of the personal and social harm sometimes produced by such awareness and acknowledgement" (p. 418) when this includes labelling.

5.6.2 Consumerism

Starting in the United Kingdom, a growing number of government policies clearly envisage the patient as a consumer of health care (Kumar, 2000; McLean, 2000; Oss, 2000; Rycroft-Malone, Latter, Yerrell, & Shaw, 2001; Stoil, 2000). This "client movement" (Williams & Lindley, 1996), "client involvement" (Kelson, 1996; Read, 1996), or "consumerist ethos" (Rycroft-Malone et al., 2001) includes patient choice, rights, and access to services and information. This consumerism is not to be confused with the "anti-psychiatry", "ex-inmates", or "survivors" (McLean, 2000; Stoil, 2000) movements which have completely eschewed the medical model of treatment for mental illness.

An implicit assumption is that greater consumer involvement in health care is both desirable and beneficial (Rycroft-Malone et al., 2001). Principles of consumerism offer choice about information disclosure, participation in health care decisions, the right to respect and non-discrimination, confidentiality of health information, and the right to challenge decisions made by health care service providers through complaints and appeals (Stoil, 2000). The nucleus of consumerism is the provision and exchange of information in these contextual factors: acuity of illness, perceived balance of power, information gaps, patterns of contact, nurse-patient relationships, and patient-centred care (Rycroft-Malone et al., 2001). In theory, the principle of consumerism appears to provide autonomy about health care decisions; however, in reality, there is considerable doubt about the extent of consumerist ethos in health care (Kumar, 2000; Meerabeau, 1998; Rycroft-Malone et al., 2001), as the physician brokers the services and decides to whom the patient will be referred (Farrell & Gilbert, 1996). In

educational and information-giving sessions patients lacking in empowerment take on passive roles (Beisecker & Beisecker, 1990).

Client involvement in psychiatry reflects the growing awareness of the impact of power imbalance on the lives of individual people and resultant challenge to professional dominance on treatment and service delivery (Kumar, 2000). Globally, service is offered with an over-reliance on hospitalization and medication while denying the adverse effects of living in a discriminating society. This restricted focus on treatment does not meet the mental health, psychosocial, and environmental needs of the patient (Berman et al., 1996). This denial of the effects of the environment undermines the client's ability to challenge and assert his or her rights (Williams & Lindley, 1996). To revolutionize current health care patterns and practices, health care must become "patient focused, flexible, accessible and responsive … allowing dialogue that is two-way, patient centered, where the patient is empowered … to take on an active role" (Rycroft-Malone et al., 2001, p. 223), thus empowering the client by providing linkages between acute care and unmet psychosocial needs (Clairborne & Vandenburgh, 2001). This suggests that qualitative research "shift" from a focus on the illness to a focus on the person (Sells, Stayner, & Davidson, 2004). This model is "person oriented rather than symptom oriented" (Chadwick, 1997, p. 577). Within any model, controversy exists; for those who consider hearing voices a valuable experience, the term recovery may not be appropriate (Thornhill et al., 2004).

5.7 Conclusion

Chapter Five has outlined the theoretical perspectives on care for people with schizophrenia. It provides ideological, historical, social, and psychological contexts of care, along with a discussion of the Health Belief Model of care. It also examined the rights of the individual with schizophrenia and provides some international context of rights. Finally, issues of consumerism and self-determination were discussed.

History and ideology have driven current theoretical perspectives of care that involve balancing the rights of society against the rights of the person with schizophrenia. These continued debates and discourses over the rights and freedoms of the mentally ill influence psychiatry and social work practices as they evolve. Ideological perspectives also influence research methodology. Choosing a postmodern, qualitative research model moves the attention of research away from the development of measurement tools for assessing insight to a consideration of what people with the illness have to say about insight. Chapter Six now outlines the research design and explains methodological decision making.

CHAPTER SIX METHODOLOGY

> It is a capital mistake to theorize before you have all the evidence. It biases the judgment. (Sir Arthur Conan Doyle, 1888, p. 3)

6.1 Introduction

Beginning with a historical discussion on modernism and postmodernism, this chapter then moves on to describe grounded theory, the methodological tradition chosen for this research, and the application of this approach in the inquiry. Interviews, focus groups, and professional and family interviews were used. Narrative analysis augmented the grounded theory analysis. Sampling criteria are outlined, along with the ethical considerations of the research. Finally, the stages of the research are described.

A strong rationale exists for choosing a qualitative research methodology (Creswell, 1998). There is a lack of research or literature that follows clients qualitatively through the lived experiences of psychosis and recovery (Forchuk et al., 2003). Geanellos (2005) offers some explanation for this gap. Firstly, most research on schizophrenia is biomedical – seeking to remedy cause and effect; and secondly, this biomedical focus limits illumination of the effects of poverty, unemployment, housing, and quality of health services. Finally, research has tended to focus on symptoms of and treatments for the disorder, rather than on understanding the experiences of persons with the illness (p. 7).

Only in the past decade have studies begun to rely on qualitative approaches to impart a deeper and more complex understanding of the experiences of a person living and coping with a severe mental illness (Roe & Kravetz, 2003). Qualitative studies will permit us a detailed view of the topic of insight using a postmodern narrative approach to understand the experiences of those with symptoms of schizophrenia as well as their development of insight into their disorder. Rich narratives, derived from in-depth semi-structured interviews, can unearth data to illuminate our understanding of the processes and factors and the hue of meanings that people with schizophrenia assign to the concept of insight. Qualitative research theory can also be used to understand and improve psychiatric practice (Goering, Boydell, & Pignatiello, 2008).

Good research contains ideological and theoretical perspectives along with a conceptual framework. A postmodern ideological paradigm (Bricker-Jenkins & Hooymann, 1986; Bryson, 1993; Dominelli & McLeod, 1989; Donovan, 1985; Mullaly, 1997; Ristock, 1993), with its focus on initial ambiguity, allows for a path of discovery (Denzin & Lincoln, 1994) and for details or findings to be obtained from the research *inductively* through the emerging data. These details or findings may be analyzed by using existing theoretical perspectives or may modify existing theory.

Social construction is the process by which people construct meaning in their lives. Social construction "stresses the social aspects of knowing and the influence of *cultural, historical, political and economic conditions*" (Payne, 1997, p. 31). Social construction, or the meaning people with schizophrenia confer upon their illness, may be seminal to the development of insight.

6.2 Modernism and Postmodernism

Critical theory has two competing perspectives: modernism and postmodernism. Modernism (the period of Enlightenment) is the result of cultural movements up to the late 19th and early 20th centuries that exacted scientific standards of rationality, objectivity, facts, replicability, and rules. Modernity sought freedom from oppression and to liberate people from the irrationalities of "myth, religion, superstition and the arbitrary use of power that characterized the Middle Ages" (Mullaly, 1997, p. 109). Modernity persisted until the 20th century when a rival perspective, post-modernism, began to take hold.

In the literature, there is disagreement about when the era of postmodernism began. Harvey (1989) argues it emerged between 1968 and 1972, as "there was a notable shift in sensibility, practices, and discourse formations, which distinguishes a post-modern set of assumptions, experiences and propositions from that of a preceding period" (p. 39). However, this "break from Enlightenment" actually began with the philosophical writings of Nietzsche, Heidegger, and Foucault (Mullaly, 1997). Nietzsche's maxim, "All credibility, all good conscience, all evidence of trust comes only from the senses" (Nietzsche, 1991, p. 452) hammers a wedge into rationality and acknowledges that truth may be found in a variety of ways as the world teems with diversity, multiplicity, pluralism, and conflict rather than sameness, unity, monism, and consensus (Mullaly, 1997). These new ways of seeking truth are referred to as postmodernism.

Postmodernism finds truth in relativism, in that, what is true for one is not true for the

other or what is true in one culture is not true in another culture. No group should define the reality or experience of another group (Mullaly, 1997). The acceptance of postmodernism is becoming widespread and, rather than competing with modernism, it is often viewed as complementary, particularly in research, where both approaches have validity. In this context, qualitative research methods have become credible as an approach to finding "truth".

With postmodernism came new ways to define and explore reality. Scientific external observation and clinical experimentation on human subjects gave way, to some extent, to a social science focusing on language: its power, discourse, meanings, and processes achieved through questioning and conversation with the subjects. This approach emphasizes the processes through which people define their identities and environments. By participating in their social world, interacting with others, and assigning meaning to aspects of their experience, they construct their social reality (Parton & O'Bryne, 2000).

Qualitative research has a different aim than quantitative research; rather than statistical representativeness, the aim is conceptual generalizability from the sample (Carrick, Mitchell, Powell, & Lloyd, 2004). "Rigorously conducted qualitative research is based on explicit sampling strategies, systematic analysis of the data, and a commitment to examining counter explanations" (Green & Britten, 1998, p. 21). Qualitative research is a "uniquely sensitive and powerful method for capturing the experiences and lived meanings of the subject's everyday world" (Kvale, 1996, p. 70). This explicit use of constructionist methodology, which analyzes and tries to make experience transparent, is central to social work practice. This transparency is attained

through interpretive work, whereby "the interpretations must include the perspectives and voices of the people whom we study … (and) researchers must assume the further responsibility of interpreting what is observed, heard or read" (Strauss & Corbin, 1994, p. 274). Analysis of the data is a critical aspect of this methodological approach.

This research strives for better appreciation of whether and how insight is acquired through the lived experiences of those with psychotic symptoms. It is difficult to quantitatively measure the experiences, processes, meanings, and power dynamics involved. Therefore, qualitative research, with its reliance on language and meaning, is a defensible and, arguably, the most suitable vehicle for exploring this phenomenon of insight development. Language orders our perceptions and instructs our behaviour, so examination of our language is critical to understanding human behaviour (Potter & Wetherell, 1987). Therefore, the acceptance of relativism, attention to language, and the perception of the person in postmodern research enhances the sensitivity of the interview, where the subjects not only answer questions prepared by the interviewer but themselves formulate, in dialogue, their own concepts of their lived world (Kvale, 1996).

The traditional Western psychiatric paradigm of objectivity and generalizability is evolving to accommodate the personal subjectivity of the psychotic experience. Using narrative and dialogue, Dolson (2005) may have been the first to identity a process on how insight develops in psychosis. He found three stages of insight development: a detection of change in lived experience (What is happening to me?), causal attribution (How did this happen?), and global construction of meaning (Why did this happen to me?). Qualitative research can "offer interesting insights into the prevention,

diagnosis, phenomenology, treatment, management, and understanding of psychiatric disorders … qualitative methods may be an increasingly appropriate methodology to answer some of the demanding research questions posed in 21st century psychiatry" (Whitley & Crawford, 2005, p. 108). Grounded theory is one of the qualitative methods used in postmodern research and is explained in the following section.

6.3 Grounded Theory

In 1967, two sociologists, Barney Glaser and Anslem Strauss, developed grounded theory (GT) research, a tradition or method of qualitative research. They believed grounded theory methodology contributed toward closing the gap between theory and empirical research (Glaser & Strauss, 1967). Since then, they have had differences of opinion over the development of grounded theory, but both have continued to research and write in relation to this methodological approach which has gained popularity in sociology, nursing, education, and other social science fields (Creswell, 1998). These quarrels have centred on Glaser's emergent theory belief, while Strauss and Corbin (1994) have developed a schema for conceptualization of the emergent data (Kendall, 1999). These debates continue. Kendall reports the debate can be settled by not viewing either method as right or wrong, but rather based on the goal of the researcher's study. Nonetheless, she states that grounded theory remains a recognized tradition for qualitative research and that "GT has a coveted place in the history of social research … and yields enduring theory grounded in data" (p. 611).

Consistent within both Glaser and Strauss's work on grounded theory is that their writing has objectivist underpinnings while giving voice to their respondents, representing them as accurately as possible, thus seeking a middle ground between

postmodernism and positivism (Denzin & Lincoln, 1994). Grounded theory is used to cultivate sociological explanations of social interactions and can construct two types of theory derived from the data: substantive and formal. Substantive theory is relevant to the data or subject area studied, as it is grounded in research from that substantive area. However, substantive theory may have broader implications, relevance and applicability to other fields and, therefore, moves toward grounded/formal theory (Glaser & Strauss, 1967). Formal theory developed from the data is judged on its adequacy, its ability to fit the phenomenon under study, to provide understanding, to be general enough to cover a range of situations but not so abstract that it loses its relevance in the context (Wells, 1995), and, as Glaser articulated, to "keep it simple" (as cited in Boychuk Duchscher & Morgan, 2004, p. 611).

The "centrepiece of grounded theory research is the development or generation of a theory closely related to the context of the phenomenon being studied" (Creswell, 1998, p. 56). Theory is a plausible relationship among concepts (Strauss & Corbin, 1994). In grounded theory, a theory is articulated near the end of the study and can assume three forms: a narrative statement, a visual picture, or a series of hypotheses or propositions (Creswell, 1998). A better understanding of insight at the theoretical level is vital to advance the design of empirical studies on insight (Markova & Barrios, 1995). Grounded theory, as a research tradition that generates theory, is a means of developing this better understanding. Furthermore, grounded theory is gaining support as a research method for qualitative research in psychiatry (Whitley & Crawford, 2005). The chief aim of research in social work is to advance theory (Polansky, 1986).

6.4 Methods of Inquiry

A multi-method study design (Bloor, Frankland, Thomas, & Robson, 2001) was employed in this study to ensure research rigor. The data gathering phase included: a preliminary inter-rator focus group, in-depth interviews with nineteen participants who have schizophrenia, two focus groups with these participants, five interviews with mental health professionals, and an interview with one family member.

In addition to grounded theory analysis, a further tool was employed in the analysis phase, when narrative analysis was applied to the data. Triangulation of research methods is often cited as a way of validating research findings. "The use of different methods in the same research project and the subsequent comparison of results is known as triangulation and is considered a highly desirable check on validity" (Whitley & Crawford, 2005, p. 110). Therefore, the researcher makes use of multiple and different sources, methods, investigators, and theories to provide corroborating evidence (Creswell, 1998) and create confidence in results. However, Bloor et al. (2001) reject the positivist notion of using triangulation to validate findings as "it assumes (wrongly) that the data produced by each method are directly comparable in respect of the order of specificity of their findings" (p. 13). Rather, they assert that multi-method study design serves to "deepen and enrich a researcher's understanding" (p. 13).

6.4.1 Interviews

Interviews play a central role in grounded theory research. Qualitative research is about listening to narratives or self-reports of those with the condition. Self-report data has potential for use as part of routine clinical care, community-based clinical research trial networks and broad quality improvement efforts, thus improving quality of care (Niv, Cohen, Mintz, Ventura, & Young, 2007). The interview is an avenue for producing narrative accounts of a person's experience. The recommendation for data collection in grounded theory research is that twenty to thirty individual audio-taped interviews be procured or sufficient interviews conducted for saturation to be reached or no new data emerge (Creswell, 1998). The researcher strove to meet these criteria. Twenty-two people were referred by mental health professionals as people who met the selection criteria. Two people who initially agreed to be interviewed did not attend on the scheduled day of interview. A follow-up phone call did not result in rescheduling the interviews, and so, in respect for their privacy and the right not to participate, no further contact was made. One man was interviewed, but clearly did not meet the research criteria due to a dual diagnosis of developmental delay and schizophrenia. Thus, nineteen people met the research criteria for inclusion. Saturation may have been reached on the seventeenth interview, as the following two interviews did not reveal new findings.

All but one of the interviews were audio-taped. Carol did not want our conversation audio-taped, but she readily agreed to have the researcher take notes. Immediately following the interview, the researcher typed the notes while memory was fresh. Technical difficulties occurred during Owen's interview and while the interview was audio-taped, it became clear during the transcription of the interview, that much of the

tape was inaudible; therefore, the researcher had to rely on notes from the interview and memory to complete the transcript.

Participant interviews were conducted in three places: the home of the participant, the office of the researcher, and a coffee shop for the interviews with Henry, Irene and the family member (FM). Professional interviews included two psychiatrists (Psychiatrist 1 and Psychiatrist 2), a registered nurse (RN), a case manager (CM), an occupational therapist (OT), and a life skills worker (LSW) for the mentally ill. All professional interviews were conducted either in the office of the participant or the office of the researcher with one exception: the OT was interviewed in the researcher's home. Tape recordings were transcribed by the researcher except for three of the individual interviews and the final focus group of study participants; a paid transcriber was utilized for these four interviews. The transcriber, an employee of the Interior Health Authority, signed a confidentiality agreement (see Appendix H). The researcher was mindful that the transcript unfolds over time, and, therefore, focused on the dialogue and meaning of the text rather than merely the written text. A memo book was used throughout the entire research process to record initial codings, thoughts, insights, questions, concerns, musings, and budding theoretical conceptualizations as the researcher zigzagged between interviews and analysis.

6.4.2 Focus Groups

The second method of inquiry was the use of focus groups. Krueger (1994) defines a focus group as a "carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive and nonthreatening environment" (p. 6). Focus groups differ from one-to-one interviews in that they collectively access group norms,

opinions, and shared knowledge rather than individual views (Kitzinger, 1995) and are considered practical for people with mental health problems where self-confidence and self-esteem are diminished. Homogenous groups offer participants a relatively safe environment and dilute the power imbalance between researcher and researched (Barbour, 2005; Owen, 2001; Whitley & Crawford, 2005). While useful to investigate "*what* participants think, groups excel at uncovering *why* participants think as they do" (Barbour, 2005, p. 746) and provide valuable insights into process. Focus groups are appropriate to answer "why" and "how" questions and allow greater probing of subject matter by taking advantage of unexpected responses (Schilder et al., 2004). The process involves the researcher "thinking on his or her feet, anticipating analysis even as data is generated" (Barbour, 2005, p. 748). Focus groups are "effective, efficient and appropriate in research studies … where the goal is to generate theories or explanations" (Morgan & Krueger, 1993, p. 9). For these reasons, focus groups are suitable as a method of inquiry to explore the fit between theory about insight development and participants' practical experiences of the processes that underpin this development. In addition, focus groups help to expand and deepen understanding of the constructs of insight held by people with the illness.

Respondent validation of research findings is an important function of focus group inquiry. This happens through a process of bringing key themes developed through grounded theory and narrative analysis back to respondents in an effort to discern levels of congruence between the researcher's and respondents' theories. Doing so can reduce the likelihood of misrepresenting respondents' views (Kruger, 1994; Whitley & Crawford, 2005). The goal of the focus group is to assist in confirming and clarifying the questions, ideas, concepts, comparisons, and properties discovered in

the data. Depending on the stage at which the focus group is undertaken, this feedback also assists in any necessary revision of the study design. Barbour (2005) suggests that "feeding back preliminary findings (to participants) … is probably the most useful approach" (p. 748), but warns against limiting the session to validating the findings, as it risks losing the potential to generate further data.

Nine focus group inquiries took place. To assist in design development, the researcher held an inter-rator focus group on January 26, 2006, with approximately 35 mental health professionals for two purposes: to present the research design, and to engage the professionals' assistance in a later inter-rator focus group to assist in validation of the findings. Research design was not changed as a result of this scrutiny, and the mental health professionals agreed to participate again later in the research as inter-rators. The second focus group was conducted on September 26, 2006, at the end of the pilot study where the researcher presented the preliminary findings to three of the five participants. A preliminary focus group is useful to explore and inform the research design (Bloor et al., 2001), refine the research questions, and inform adjustments "to critical logistical factors" (Krueger, 1994, p. 69) for the later, larger portion of the research. The third focus group was held on November 8, 2006. Validation and support from both the participants and the inter-rator focus group boosted researcher confidence that the research design was adequate to produce the knowledge it was designed to seek. No change to the research methodology was made, based on the feedback from the preliminary focus group. Once the final interview had been conducted and analysis of the data was largely completed, the researcher held the fourth focus group, on October 3, 2007, for all study participants. While all participants were invited, some were clear at the time of the initial interview

that they did not wish to attend, some who had initially agreed to attend called to cancel their participation in the focus group, and one person did not respond to the invitation. Therefore, seven of the nineteen participants took part in the final participant focus group. Findings, themes, and theories from the data were presented with robust agreement of accuracy from the group.

A fifth focus group was held in British Columbia, Canada, on September 26, 2007. To employ a form of inter-rator reliability, the researcher presented, for analysis, the initial coding from the entire study to a group of mental health colleagues that included: community case managers, community and hospital occupational therapists, mental health social workers, registered nurses, and psychiatrists. The coded data presented to colleagues concerned theoretical ideas, not potentially identifying information provided by participants in the semi-structured interviews or other focus groups. Feedback discussion was received and incorporated into the researcher's understanding of the findings. This further analysis of the coding allowed for comparison and discussion of the findings, and greater potential to generate a theory. An additional advantage is that inter-rator reliability has the potential to reduce investigator bias (Mays & Pope, 1995).

A series of four inter-rator focus groups was held in Christchurch, New Zealand, in February 2008. The focus groups (29 mental health professionals consisting of an early intervention team, two adult community based teams and one team that supported families) were delivered the findings and analysis of the data. An agreement questionnaire (see Appendix J) was developed as a way to determine a) if the research findings made sense, and b) if the research findings could guide

professional mental health practice. Appendix K documents the results of the questionnaires and demonstrates high agreement that the findings may be able to guide professional mental health practice.

6.4.3 Professional and Family Interviews

The third method of inquiry involved individual interviews with professionals and a family member. The professionals represented those who professionally support people with schizophrenia. The researcher's initial intention was to interview a family member supporting a person with schizophrenia, but who was *not* related to any of the research participants. However, unbeknownst to the researcher and only detected via information revealed during the interview, the family member interviewed *was* related to one of the participants. It is not known to the researcher if either the participant or the family member was aware of the other's involvement in the research as neither disclosed this. Gathering both professional and family perspectives produced corroborating or contrasting evidence on how insight is developed.

6.5 Analysis and Interpretation of the Data

Five phases of data analysis led to the interpretations found in this thesis. Firstly, the data analysis was broken into two sections: the transcriptions of the interviews and the open coding of the data. Secondly, subjecting the data to a systematic, yet dynamic set of questions was revealing. Thirdly, relying on literature assisted in making sense of the codes and emergent linkages between codes. Fourthly, using a manual "cut and paste" method assisted in the further development of the analysis and interpretation of

the date. Finally, building a narrative analysis into the research design was a tool for interpretation of the data and reducing research bias.

Interviews were transcribed by listening to the audio tapes generated at the time of the interview and typing not only, word for word, the person's narratives, but, including punctuation that reflected the nuances and emphasis of speech. This captures the full meaning of the narratives for any reader of the transcript. Transcription also served as a first analysis of the data as the researcher "re-heard" and reflected upon the meanings of the stories provided by the participants. As the transcripts were completed, the researcher fractured the data into open codes and used NVIVO software as a tool for storing and labeling the codes.

Secondly, once the open codes were completed, the researcher used questioning to establish linkages between each open code. Basic questions such as who, what, where, why and how were used. For example, examining the open code, *learning about the illness*, the questions asked were: Who learned? Who learned what? Who taught? What was taught? What was learned? When was this learned? When did this occur? Where did this happen? Where were they? Why did they learn? Why was it taught? Why did they hear it? How did they learn? How was it delivered/received? Logging the results of the questioning in a memo book assisted the researcher in asking additional questions, generating more insights and identifying additional linkages about the data.

Thirdly, the researcher relied heavily on literature to make sense of the data. Zigzagging between emergent codes/subjects/concepts and scholarly literature on that

subject/concept. Fuller knowledge of the subject matter assisted and guided a richer interpretation of the data and generated avenues to explore in further data gathering.

Fourthly, employing a manual "cut and paste" method assisted with the analysis. The researcher printed all open codes, and with scissors, cut them apart into small labels. The labels were then arranged to identify processes. This cut and paste method revealed the *Process of Insight Development*. From this process, other theoretical concepts of the study were revealed. For example, once the action period (later renamed the *Dynamic Period*) was identified, the acronym, *C.L.A.R.I.T.Y.* emerged to fit the labels reflecting the steps of dynamic action toward wellness.

Finally, building a narrative analysis into the research design not only served to reduce researcher bias but also provided an additional method to analyze and interpret the data. The grounded theory analysis revealed a theoretical model that made sense to me, as a researcher and practitioner. As there is risk in "wanting" the findings to be what they seem, a second type of analysis, called the narrative analysis, was utilized to help modulate any research bias that existed. In addition, a second and separate type of analysis serves to support, expand, challenge or refute the original analysis of the grounded theory methodology. Therefore, a narrative analysis was selected as the second method of analysis.

Narrative analysis is premised on the belief that people construct life histories to make sense of and to gain control over their lives (Roe & Ben-Yishai, 1999). These stories or life histories use language to construct reality (Freedman & Combs, 1996) and hermeneutics are employed to interpret the meaning of the conversation and text

captured in the story. Hermeneutics is the study of the interpretation of written texts. This study of texts is undertaken with:

> a view to interpreting them to find out the intended or expressed meaning, in order to establish co-understanding, or possibly even a consent; and in general to mediate traditions so that the historical dialogue of mankind may be continued and deepened. (Kvale, 1996, p. 47)

Linguistic competence is required to look for the narratives (stories and themes) within the interview. The clients' narratives of their subjective experiences are ultimately valued in shaping social work intervention (Kam-shing, 2002).

These narratives or themes have three points of reference: recurrence of ideas, repetition, and forcefulness of verbal and non-verbal cues (Overcash, 2004). Once themes have been identified, the second task is in developing "convincing insights and opening new vistas for understanding the phenomenon investigated" (Kvale, 1996, p. 201). Often the storytellers of clinical narratives construct stories about their progression through treatment of the disorder in a manner that allows the experience to be understood by both the storyteller and the story listener (Park-Fuller, 1995). Assessments of insight at the narrative level may "reveal correlates and aspects of aetiology of poor insight not uncovered by traditional measures" (Lysaker, France, Hunter, & Davis, 2005, pp. 148-149). In addition, the way a person tells a story of his or her life shapes their experience of their condition and provides both a "context for and an index for change" (France & Uhlin, 2006, p. 55).

Mining these stories constructed by people with the illness may provide important "context and index" for insight development. Qualities of self-experience embedded

into personal narratives may be linked to objective and subjective assessments of recovery (Lysaker et al., 2006). What is not said or talked about can be as telling and informative as what is said; story gaps often provide important clues.

Five phases of data analysis led to the interpretations found in this thesis. Using multi-methods of data analysis can lead to richer, more complex and fuller interpretations of the narratives provided by the participants.

6.6 Sampling Criteria

Sampling in qualitative work is purposive (Denzin & Lincoln, 1994; Whitley & Crawford, 2005). Purposive sampling deliberately recruits participants who are "information rich" (Denzin & Lincoln, 1994, p. 73) or "homogeneous" (Creswell, 1998, p. 118), allowing the study to be "grounded in a local context" (Whitley & Crawford, 2005, p. 110). Study participants recruited using the snowball method can assist in identifing "cases of interest from people who know people who are information rich" (p. 119).

Requests for participants were made to the local chapter of the Schizophrenia Society of British Columbia, The Canadian Mental Health Clubhouse Association, and within the Interior Health Authority's Mental Health community. All were eager to facilitate access to potential participants. Case managers (CM) and physicians in the mental health community willingly provided recruitment packages to their "information rich" clients. (Appendix F and G are part of the recruitment package). The clients, once approached, signed a Consent to Contact Form (Appendix G) that was then provided to the researcher who initiated contact and made interview bookings. The selection criteria for participants were:

a. ***Have a diagnosis of schizophrenia based on DSM-IV criteria***. This criterion was necessary to keep the sample homogeneous and ensure the likelihood that psychosis had occurred. This criterion also lent itself to obtaining an information rich population.

b. ***Several hospital admissions in the past due to psychotic symptoms.*** Multiple hospital admissions may be an indicator that, in the past, the participant may not have had good insight into their illness. It is an indicator that psychosis probably existed.

c. ***Be identified as having good insight by others or achieved at least a two-year period of stability in their health.*** This criterion may be an indicator that the participant has developed or is developing insight into their illness.

d. ***Do not have current alcohol/ substance abuse or dependence according to the DSM-IV criteria.*** This exclusion was required to maintain homogeneity and to reduce confounding factors.

e. ***Are between 20 and 65 years of age***. Again, to ensure homogeneity, this age criterion eliminated the responses of children and responses of the aging adult which have potential to confound the findings of the study.

f. ***Have access to support from family, physician or mental health worker***. This criterion shaped uniformity in terms of community support and thus eliminated confounding differences of having support person(s) versus not having support person(s).

g. ***Have no other cognitive impairment such as brain injury, autism, or development disability.*** This criterion assisted in limiting variables of impaired cognition, thus reducing confounding variables.

Sociodemographic information collected on the participants included: age, gender, education, ethnicity, religious affiliation, if any, marital status, housing, employment, parenting responsibilities, age of onset, illness duration, number of hospitalizations, and length of stability. In addition, information regarding current medications was also collected (see Appendix D). It was hoped that visible minority participants might be nominated for the study. However, no people of visible minority were nominated, however, one person did self identify as part aboriginal.

6.7 Ethical Considerations

Psychiatric research guides the provision of care to those suffering from schizophrenia. Despite the importance of psychiatric research, public concern in response to prior unethical experiments has necessarily placed limits on such research. "Dubious experiments, violating fundamental ethical and possibly legal standards and causing human subjects pain and harm - often without their informed consent are not, however, what the public should expect from science" (Lehrman & Sharaav, 1997, p. 227). Standards of treatment and national and international codes dealing with the ethics of human experimentation arose out of the Nuremburg trial. The Nuremburg Code (1947) "unequivocally established that the individual subject's rights - through informed, voluntary consent and welfare must never be subordinated to the interests of science and society" (Wilson & Stanley, 2006, p. 228). Disturbing is this statement concerning psychiatric research: "In no instance was the expression of concern about abuse in psychiatric patient populations greater than in the area of schizophrenia" (Lieberman, 1996, p. 19). Our concern to protect the vulnerable potentially places researchers in a double bind. Researchers are trying to respond to increasing pressure to demonstrate valid informed consent while ethicists are demanding stringent

standards with "potentially stifling effect on research into the severe disorders afflicting those individuals it seeks to protect" (Dunn & Jeste, 2003, p. 81). Balance between advancing science and protecting the vulnerable is difficult to achieve.

Due to the potential vulnerability of people with the illness, psychiatric research carries certain risks and/or ethical issues that need addressing. A participant is deemed vulnerable if the information provided to them is not accurate and balanced, if the person is not capable of making a decision about participation in the research, or if their decision is not autonomous and voluntary (Iacono & Murray, 2003). Ethical concerns surrounding research relate to harm, consent, deception, privacy, and confidentiality of the data (Denzin & Lincoln, 1994) but also competence, informed consent, conflict of interest (Lieberman, 1996), boundary violations, and risk-benefit issues (Saks, Jeste, Granholm, & Palmer, 2002). The next section addresses these areas of ethical concern in relation to the research.

6.7.1 Harm

The harm and risk/benefits of the research must be examined and explained to participants. Use of rational reasoning is a "logical chain of thoughts, demonstrating that an individual weighs the risks and benefits of participation in the process of eventually arriving at a final decision" (Misra & Ganzini, 2004, p. 117). DuVal (2004) synthesizes the risk/benefit equation: "An ethically appropriate framework for psychiatric researcher ethics balances rigorous protections for human subjects with a recognition of the enormous social and individual benefits arising from well-designed and ethically conducted scientific research" (p. 56). While an increased risk of suicide accompanies increased insight (Crumlish et al., 2005), other factors contribute to

suicide risk such as depression, previous suicide attempts, drug misuse, agitation or motor restlessness, fear of mental disintegration, poor adherence to treatment, and recent loss (Hawton, Sutton, Haw, Sinclair, & Deeks, 2005).

Fewer years of treatment also increases risk of patient suicidality (Schwartz & Smith, 2004). Increased insight predicts depression at six months and attempted suicide at four years (Crumlish et al., 2005). Insight is significantly associated with an increase in depression and poorer subjective quality of life (Karow & Pajonk, 2006). While some patients may become depressed after acknowledging their disorder, treatment-related changes in awareness are associated with a positive outcome relative to suicide risk (Bourgeois et al., 2004). Lewis (2004) differentiates conditions that mimic depression, such as mourning, aprosodia, and negative symptoms, and describes the role of mourning in the attainment of accurate, usable insight that can reduce suicide risk. Awareness of negative symptoms and delusions, and the pejorative beliefs about these symptoms, seem to correlate with increased suicidal ideation (Amador et al., 1996).

Further research, better treatment, an increased sense of self-efficacy, and treatment compliance may actually reduce suicide risk. Research may lead to treatment interventions that benefit other sufferers of schizophrenia, may improve quality of life for families, increase social function for the sufferer, and economically benefit society through decreased hospitalizations.

To mitigate risk in research, three measures need to be implemented: voluntarism, no large monetary reimbursement, and after support for distressed participants (Iacono &

Murray, 2003; Saks et al., 2002). Voluntarism is an "essential component of decision-making capacity to consent to research and assures that a subject is free to agree or decline to participate in research" (Misra & Ganzini, 2004, p. 117). Mentally ill populations are vulnerable to coercion (Saks et al., 2002) by people viewed to be in positions of authority (Misra & Ganzini, 2004). Therefore, it is necessary to ensure that the patient understands that participation in research can be refused or withdrawn at any time. As well, large monetary reimbursements may serve as "undue influence on subjects' decisions" (Misra & Ganzini, 2004, p. 117), as 57% of patients in one study cited potential resource gain as one of the reasons for participation (Kaminsky, Roberts, & Brody, 2003). To avoid undue influence, no monetary reimbursement was offered in this study.

As demonstrated earlier, globally, the illness of schizophrenia burdens the sufferer, their family, and society, so urgency exists to find solutions. The personal and public benefits of understanding how insight develops and might be enhanced, would appear to outweigh the risks posed by the study. These risks were further mitigated by the selection criteria and safeguards that were established. None of the participants exhibited or acknowledged distress as a result of the interview; however, the researcher directed them to their assigned mental health workers, care providers, or physicians to provide support in the event that some distress should occur.

6.7.2 Informed Consent

Since the institution of the Nuremburg Code (1947), "every investigator is legally and morally required to disclose fully all relevant information that would enable a potential subject to make an informed decision" (Lehrmam & Sharav, 1997, p. 232).

Consent must be voluntary and competent (Saks et al., 2002). In this study, all participants were voluntary, under no compulsion or obligation to participate, and had the right to withdraw from the research at any time. To avoid deception, the consent information form (Appendix A) clearly outlined the purposes and expected outcomes of the research, the role of the researcher and the expectations of the participant, prior to the participant's signing of the consent form (Appendix B).

6.7.3 Competency

The competence of the mentally ill person to provide informed consent is a much more difficult issue to assess. People with severe intellectual disability are considered vulnerable to exploitation in research (Iacono & Murray, 2003). The neurocognitive deficits associated with schizophrenia "may impair the capacity to understand a study and thus provide 'true' informed consent" (Mathew, 2002, p. 564). Deficits in emotional functioning may be present as well (DuVal, 2004). Therefore, the researcher undertook a rigorous approach to full and informed consent to ensure the participant fully understood what his or her consent entailed.

Minimal standards for informed consent include the "demonstrated ability to understand information that is relevant to the choice being made. Firstly, the person would need to (1) have a preference between options and (2), be able to communicate his or her choices between options" (Dresser, 1996, p. 43). This concept of choice is well supported (Misra & Ganzini, 2004; Saks et al., 2002). The United States legal standard for decision making includes understanding, appreciation, and rational reasoning (Misra & Ganzini, 2004). These standards were applied in this research.

In an attempt to assess the understanding of the participant, a two-part consent form is widely used although with differing measurement instruments (Dunn & Jeste, 2003; Iacono & Murray, 2003; Miller & Willner, 1974). This research utilized a two-part consent. Firstly, the letter of introduction (Appendix A), as outlined above, was followed by the consent form (Appendix B). Secondly, a set of questions was used that contained additional explanation should initial responses indicate poor decisional capacity (Iacono & Murray, 2003) (Appendix C). This "cueing" was used to facilitate understanding of the consent form (Combs, Adams, Wood, Basso, & Gouvier (2005). All consent documents met the Fiesch scores of readability (Mathew, 2002) to ensure that consent was fully understood.

6.7.4 Confidentiality

Confidentiality and privacy must be rigorous in psychiatric research. The raw data in both audio-taped and transcribed form were coded using pseudonyms. The data will be maintained in locked storage in the researcher's home or office for up to five years. Privacy during the interviews was considered and only meeting places where the participants felt comfortable were selected. As noted earlier, these included the participants' homes, the researcher's office and home, and on two occasions, a coffee shop. Participant focus groups took place in the researcher's office, and inter-rator focus groups took place in the mental health agencies, hospital, and one at the University of Canterbury in New Zealand.

6.7.5 Boundary Violations

An ethical researcher will ensure there are no boundary violations. Researchers are warned to stay true to their role as a researcher and not regard her or himself as a "treater", or lead the participant into thinking that they have that role (Saks et al., 2002). " … the investigator's goals are the successful accomplishment of the study and the well being of the patient; whereas, the clinician's sole role is the well being of the patient. These interests have potential for conflict" (Lieberman, 1999, p. 21).

Ideally, patients involved in research should have a clinician assigned who is not involved in the study, but as Leiberman laments, "on a practical level, this would be time consuming and cumbersome to carry out, and thus complicate the already difficult process of clinical research" (p. 20). There was some possibility that this researcher may have had prior contact with potential participants when in a "treater" role. Saks et al. (2002) remind researchers that this role change may have some adverse impact on the participants as they may experience some role confusion. Ideally, participants should be excluded when previously "treated" by the researcher, but given the small number of participants gathered for the study, and the fact that there was only one instance where the researcher had formally been in a "treater" role, this was handled through clear role delineation as part of the informed consent process.

6.7.6 Ethics Approval

Prior to ethics approvals, the research process involved the submission of a research proposal. Once accepted, the formal enrolment as a PhD student with the University of Canterbury took place on January 6, 2006.

Ethics approvals were required from two authorities: The University of Canterbury (UC), Christchurch, New Zealand, and the Interior Health Authority (IHA) in Thompson Cariboo Region, British Columbia, Canada. The IHA's acceptance of a proposal for ethics approval was contingent upon ethics approval from the University of Canterbury. A request for clarification was received from IHA on May 23, 2006. Clarification was provided and deemed satisfactory. The IHA considered the application and gave tentative approval on June 6, 2006, pending the University of Canterbury's approval (IH Research File Identifier 2006-012). The University of Canterbury provided ethics approval on June 12, 2006 (HEC Ref. 2006/4), and a copy of the approval was provided to IHA. Therefore, both approvals were finalized on June 12, 2006, following the exchange of each authority's letter of approval. Neither the British Columbia Schizophrenia Society (BCSS) (Jane Duval), nor the Canadian Mental Health Association (CMHA) (Cathryn Hume), required a separate consent process; both organizations reported satisfaction that consent processes were pre-approved by the University of Canterbury Human Ethics Committee.

In February 2008, an agreement questionnaire was delivered to inter-rator focus groups in New Zealand. The Chairperson of the University of Canterbury Human Ethics Committee deemed these questionnaires did not require further ethics approvals as they were delivered to mental health professionals and related to the carrying out of their professional work, therefore, did not pose any expectable undue risk of harm.

Ethical standards guide psychiatric research. The researcher upheld principles of

"respect, beneficence and justice" (Denzin & Lincoln, 1994, p. 89) which align neatly with the University of Canterbury's principles of justice, safety, truthfulness, confidentiality, and respect. The British Columbia Association of Social Workers Code of Ethics (1994) demands that social workers:

> … believe in the intrinsic worth and dignity of every human being and are committed to the values of acceptance, self determination and respect of individuality … to the development and disciplined use of scientific knowledge regarding human and societal behaviours … and to the achievement of social justice for all. (p. 7)

These principles are combined with rigorous research standards in an effort to forward scientific knowledge for society. The prevailing attitude of respect, and the ethical standards adhered to throughout the research process minimized the possibility of "spoiling the nest" (Denzin & Lincoln, 1994, p. 93) for future research. Once ethics approvals were received in June 2006, the research was able to commence.

6.8 Supervision

Principal supervisor for the research was Dr Kate van Heugten, Head of the School of Social Work and Human Services and Director of Te Awatea Violence Research Centre, University of Canterbury, Christchurch, New Zealand. Her responsibilities included primary academic supervision of the PhD process, qualitative methodology, social work perspective, policy and practice implications, thesis writing, and oral examination preparation. Co-supervisor, Dr Kurt Buller, Head of Clinical Psychiatry, Royal Inland Hospital, Kamloops, British Columbia, Canada, was responsible for the day-to-day monitoring of the research, assisting with local ethics approval, interviewing and recruitment strategies. He also assisted with the analysis of findings and theory development. Associate supervisor was Dr Elliot Goldner, Professor, Faculty of Health Sciences, Simon Fraser University, Vancouver, British Columbia,

Canada, and Chair, Advisory Committee on Science, Mental Health Commission of Canada. He assisted with the conceptualization of the mental health research and with question development.

Regular email contact and teleconferencing took place over the three years of study and the researcher provided monthly progress reports to the supervision team. Once the research was concluded, written submissions were provided each fortnight to the supervisory team, and this was followed by regular teleconferences.

6.9 Research Stages

Table 1 below outlines and summarizes the research stages and elements contained within each stage. This is followed by a brief outline on the research stages.

Table 1: Research Stages

Research Stages		
Research Steps	**Stages**	**Date**
Step One	Enrolment date Inter-rator focus group on research design Proposal acceptance registration University of Canterbury Human Ethics Approval Interior Health Authority Ethics Approval Five interviews with study participants Transcription and data analysis Pilot study focus group Inter-rator focus group	January 6, 2006 January 26, 2006 June 6, 2006 June 12, 2006 June 12, 2006 July - September 2006 July - September 2006 September 26, 2006 November 8, 2006
Step Two	Interviews of 10 participants Transcription and data analysis Interviews of 4 additional participants Professional interviews	July 2006 - December 2006 July - December 2006 January - February 2007 May - July 2007
Step Three	Transcription and data analysis Participant focus group 6 Inter-rator focus groups	January - December 2007 October 3, 2007 September 2007 - February 2008
Step Four	Documentation/Writing of research	September 2007 - November

	findings/Theory development	2008
Step Five	Dissertation defence	February 2009

Step One of the research process included the formal enrolment of the student on January 6, 2006 as a PhD candidate with the School of Social Work and Human Services, University of Canterbury, and an inter-rator focus group to assist with research design. Once ethics approvals were in place, the research was registered on June 6, 2006, and the pilot study commenced.

Following participant recruitment, five audio-taped interviews took place, each of one to one-and-a-half hour duration and based on a set of predetermined "process" questions. These semi-structured/open-ended foundation questions were a guide designed to launch the researcher and the participant(s) into a discussion to evoke narratives from the respondent(s) on the critical issues of insight construction for them (Appendix E).

Upon completing the interviews, the researcher and/or an assistant transcribed the audio tapes and data analysis began using grounded theory analysis and narrative data analysis. A focus group was held on September 26, 2006, and the preliminary findings were presented. As well, an inter-rator focus group of approximately 35 mental health professionals was held on November 8, 2006. The pilot study data was absorbed into the main study data.

Steps Two and Three represent the major research portion of this study. Personal interviews of a further fourteen participants and a family member took place. Transcribed data was used for careful, detailed data analysis and in-depth grounded

theory methods of open, axial, and selective coding. NVivo 7 qualitative software was used to assist in coding of the findings which assisted the researcher to look for propositions, comparisons, properties, causal conditions, consequences, and intervening conditions. Upon final transcription and preliminary coding, five professional interviews and one family member interview took place and these were followed by a focus group of the study participants and a series of six inter-rator focus groups.

Step Four is this documentation of the study findings. This final thesis reflects the identification of findings in a written and visual manner; identification of the central themes/phenomenon that emerged from the data; theoretical implications of the findings; theory development; discussion of the findings; emerging policy and practice implications; recommendations for further research; limitations of the study and conclusions. The researcher created a visual model of coding paradigms and finally, searched for a central phenomenon to describe the process of insight development.

Step Five in the doctoral research process consists of the submission of the thesis and its oral defence. The resumé outlining the education and experience of the principal researcher is also included (Appendix I).

6.10 Conclusion

Based on the arguments for and against modernist and postmodernist research, and considering that gaps exist in qualitative research for people with schizophrenia, this researcher chose grounded theory as the primary methodological tradition. Grounded

theory is the research tradition that moves away from objectivity and, instead, focuses on the telling clues available within the subjective minds of the individuals with schizophrenia. These clues, when we listen to them, guide our understanding of what produces insight in schizophrenia. Narrative analysis was used to augment the grounded theory analysis. The sampling criteria were outlined, along with the ethical considerations of the research. Finally, this chapter set out the stages of the research in table form followed by a brief description of each stage. The following chapter is brief and will outline the demographics of the sample used for the study and introduce the reader to the people in the sample.

CHAPTER SEVEN INTRODUCTION TO SAMPLE

> Randy: What it is like? What it is like? The best way I can explain to you what the voices are like is like wearing a walkman and turning up to 2 or 3 and going on with your daily life. If you … put on your walkman and then went into the hospital and did your daily routine … it would get to you, wouldn't it?.You would start to think, I can't hear you, why can't I turn this down. I can't do that. The only way that happens is with medication.

7.1 Introduction

Chapter Seven introduces the demographical details of the participants in the sample and provides a map of the process of insight development to guide the reader through the structured presentation of findings detailed in Chapters Eight to Thirteen.

In qualitative research, the findings are the theoretical constructs of the researcher based on data analysis and consideration of the literature. The raw data include the number of participants who speak about a certain concept or code as well as the frequency or intensity with which a particular code was referred to. All findings described reflect the robustness and clarity of sources referring to a particular code or concept. This data is then analyzed and organized into useful categories for understanding.

Chapters Eight, Nine, Ten, and Eleven document the findings of the study. The findings reveal three stages of insight development: the *Period of Chaos*, the *Dynamic Period,* and the *Period of Wisdom*. These four chapters describe how people stumble through an illness steeped in stigma and terror toward insight and recovery. Paradoxically, this painful "stumbling" appears to be the mechanism "tumbling the lock" on insight. Additionally, there are *Four Phenomena of Influence* to the process

of insight development, and these influences will be the focus of Chapters Twelve and Thirteen. This current chapter introduces the people of the research sample, and then, in the following chapter, the reader is immersed into the chaos of the life of a person with schizophrenia.

7.2 The Participant Sample

Twenty people with schizophrenia were interviewed who appeared to meet the criteria for the study. Unfortunately, but necessarily, one of the participants was disqualified from the study as it became clear during the interview that he had a dual diagnosis of developmental delay and schizophrenia. He, therefore, did not meet study criteria and it was not clear that he was capable of informed consent. His interview was not transcribed. Sample size was nineteen participants. They are introduced here in alphabetical order. Five professional interviews were also conducted.

Art (43) is Canadian and of Scottish descent. He is a Roman Catholic, has three years of post-secondary education, is single, and lives alone in an apartment. He has supported part-time work at the mission. He has a current CM. His first break was at age 16 and he has not been hospitalized for 5 years. He listed his medication as Clozaril, Paxil, and clonazepam.

Carl (65) was the oldest participant. He is Canadian and of Scottish and English descent. He has a grade 8 education and is Protestant Christian. He is single and lives alone in a rented apartment. He listed his employment as retired. He has a current CM. He was 22 years of age at first break and has not been hospitalized for 27 years, despite more than 15 previous hospitalizations. He is on risperidone.

Carol (41) is Canadian, but born outside of Canada. She holds a Bachelor degree and volunteers at the mission. She has a partner who parents their teenage son, but she does not live with them. She is of Greek Orthodox faith. Carol was 26 when she had her first break and currently has a CM. She has not been hospitalized for four years. She is currently taking flupenthixol injections every three weeks, Risperdal, benztropine, and clonazepam.

Elly (29) is Canadian. She is of Romanian, Czechoslovakian, Scottish, and English descent. She was the youngest participant in the sample. She is a Buddhist. She has one year of post-secondary education and is an artist. She lives in a common-law relationship in a rented apartment. She was diagnosed at age 19 and has not been hospitalized for 5.5 years. She was working, but is currently on a disability pension.

She does not have a CM, but is closely aligned with her psychiatrist. She listed her medication as Piportil, clonazepam, benztropine and Wellbutrin.
Ham (49) is Canadian and Caucasian but declined to list his ethnicity and listed no religious affiliation. He has a grade 12 education, is single and lives alone in an apartment. Ham did work at a mill, but currently lists his employment as retired. He has a current CM. He was diagnosed at age 22 and has not been hospitalized for 11 years. He listed his medication as Clozaril.

Hannah (50) is Canadian and listed being of Welsh, Scottish, French, and European background. She has two years of post-secondary education. She is an Anglican Christian. She is single, and lives alone in a townhouse co-owned by her mother. She does not have and has never had a CM, but was connected closely with her psychiatrist in the early years of her illness. She cited volunteer work as her employment. She was diagnosed at age 25 and has not been hospitalized for 13 years. She is on Risperdal.

Henry (44) is a Canadian of Italian descent. He has one year of post-secondary education and is a Roman Catholic. He is single, lives with his mother in their own home. He cites volunteer work but has a home-based business. He does not have a current CM. He was 24 years of age at first break and has not been hospitalized for 14 years. He listed Risperdal as his current medication. He is an uncle to two young boys.

Ingrid (57) is Canadian of Norwegian descent. She is a twin. She is a Christian of the Anglican faith. She has one year of post-secondary education. She has been married for 36 years and lives with her husband and son (32) in their own home. She listed employment as volunteer work. She does not have a current CM. She was 32 years of age at first break and has not been hospitalized for 24 years. She is on Pimozide, benztropine and clonazepam. She has two sons, and a grandson with autism.

Irene (52) is Canadian but did not report her ethnicity. She is a Christian of the Methodist faith. She has two years of post-secondary education. She is single and lives alone in a rented apartment. She worked for years at the local institution but is now on a disability benefit and lists retirement as her occupation. She has a current CM. She was 19 years old at first break and has not been hospitalized for 14 years. She listed Risperdal and Celexa as her medications.

Norm (52) is Canadian and listed his ethnicity as a WASP (White Anglo Saxon Protestant) and is a Christian affiliated with the United Church. He holds a Bachelor degree and is widowed. He currently lives alone in a mobile home he owns. He volunteers and has not been able to return to pharmacy work. He does not have a CM, nor has he ever had one. He was 32 years of age at first break and has not been hospitalized for 14 years. He has no children. He listed his medication as Risperdal, Zoloft and benztropine.

Olive (44) is Canadian and of German and Aboriginal descent. She has a grade 12 education and is of the Jehovah Witness faith. She is single and lives alone in a rented apartment. She works part time at a local restaurant and has a current CM. She was 16 years of age at first break and has not been hospitalized for five years. She listed her medication as Effexor, Seroquel and trazadone. She is a parent of grown children.

Owen (33) is Canadian of Italian and Scottish descent. He did not list any religious affiliation and has a grade 12 education. He lives with his father in a home owned by his father. He cited his paper route as his part-time employment. He does not, nor has he ever had a CM. He was 22 at first break and has not been hospitalized for 11 years. He cited clozapine as his current medication.

Patty (57) is Canadian of Scottish descent. She has two years of post-secondary education, is a Christian and belongs to the United Church. She is divorced, lives alone, and listed volunteer as her occupation. She has a current CM. Patty was 49 years old at first break and was parenting her teenage girl at that time. She has not been hospitalized for 6 years. She is a parent of grown children and is a grandmother. She is on clozapine and Dilantin for her seizure disorder.

Peter (41) is Canadian and of Norwegian and Irish descent. He is a Christian fundamentalist. He holds a Bachelor degree, is single and lives in a mobile home owned by his father. He is not employed, and has a current CM. He was first diagnosed at age 28 and has not been hospitalized for 3.5 years. He listed his medication as Seroquel and Fluanxol injectable.

Randy (39) is Canadian and of Russian descent. He was adopted and has a grade 10 education. He has no religious affiliation. He is single and lives in a rented apartment. He does not work and has a current CM. He was 29 years of age at first break and has not been hospitalized for 8 years. His medications are Clozaril, risperidone, Prozac, clonazepam, Pariet and Lipitor. Randy continues to experience significant troubling positive symptoms.

Sam (41) is Canadian and of German descent. He has one year of post-secondary education and has no religious affiliation. He is single and lives alone in a rented apartment. He volunteers and has a current case manager (CM). He was 23 at first break and has not been hospitalized for 14 years. He listed his medication as Celexa, Haldol injectable every 3 weeks, Cogentin and clonazepam.

Sarah (40) is Canadian of German descent. She is a Christian, has some courses toward a first-year post-secondary education, is single and lives in a mental health group home. She has a current CM. She has volunteer employment. She was 21 when first diagnosed and has not been hospitalized for seven years. She listed risperidone, Seroquel and zopiclone as her medications.

Yvette (61) is Canadian of Norwegian and Irish descent. She has a grade 10 education, is divorced and lives alone in an apartment. She has no religious affiliation. She baby-sits part time for her work and has a current CM. She was diagnosed at age 6.5 years and it has been six years since her last hospitalization. She has grown children and two grandchildren. She is on Fluanxol injections every two weeks. She has been sober for 5.5 years.

Zack (52) is Canadian and of Scottish, Irish, and Ukrainian descent. He has no religious affiliation, is single, and lives alone in a rented apartment. He has a grade 12

education. He has no current CM, but has had a CM in the past. He was diagnosed at age 15 and has been out of hospital for 22.5 years. His medication regime is Risperdal, benztropine, and amitryptiline.

All study participants live in Canada. Gender breakdown was nearly even at ten males and nine females. The mean age of the sample was 46.8 years; the youngest participant was 29 years of age and the oldest 65 years of age. Marital status revealed that sixteen were single people, one was divorced, one was married, one lived in a common-law relationship, and one was a widower. Fourteen rented an apartment, one co-owned with a family member, one owned their own place of residence, another participant's father owned the mobile home in which he lived, two lived with family, and one lived in a mental health family care home.

Nine participants described their employment as volunteer work, three reported being retired, three had worked in the past, one had never worked, four listed their work as part time: one at a local hamburger diner, one delivered newspapers, and another was a support worker at a drug and alcohol recovery centre (this appeared to be supported employment). The fourth provided part-time day-care for two children. One participant had a home-based business but listed his work as volunteer. Three of the participants were parents, but only one currently had her son living at home with her. Fifteen of the people have or have had a CM; four had never had a CM. The average age at first break was 23.5 with females having the greatest variance in age at first break (6.5 years to 49 years) compared to males (15 years to 29 years). The average number of hospitalizations was 5.6 with the lowest being two and the highest in excess of fifteen hospitalizations. The average length of time since their last hospitalization was 11.28 years. Average education was 12.8 years of schooling with

the males having the greatest variation in education (grade 8 to university graduate) while the female range was grade 10 to university graduate.

Spiritually, six participants did not describe any belief in a formal deity, nine described themselves as Christian, two as Catholics, one a Jehovah Witness, and one as Buddhist. All were Canadians with European ancestry, although one person identified herself as part Aboriginal, and one was born outside of Canada.

Antipsychotic medications prescribed were: one person on Haldol (haloperiodol), one on Orap (pimozide), six persons on risperidone (Risperdal), four persons on Clozeril (clozapine), two persons on Fluanxol (flupenthixal), one person on pipotiazine (Piportil), one person on Seroquel (quetiapine), two persons on a combination of clozapine and risperidone, and one person on a combination of flupenthixol and resperidone. Interestingly, these participants, deemed by mental health professionals to be people with schizophrenia on their community caseloads and to have the best insight and recovery into their illness, continue to be inundated by significant and persistent auditory hallucinations. This persistency of symptoms, despite pharmacological treatment, is noted in the literature (Shergill, Murray, & McGuire, 1998). This research is testimony to their stories of tragedy and triumph.

7.3 The Professional Sample

Corroborative professional evidence bolsters the reliability of the data. Five professional interviews were conducted. These professional interviews included two psychiatrists (Psychiatrist 1 and Psychiatrist 2), an occupational therapist (OT), a

registered nurse (RN), and one life skills worker (LSW). One family member (FM) was also interviewed.

Psychiatrist 1: Female psychiatrist and trained in spiritual formation and spiritual direction; MD and FRCPC. Private practice.

Psychiatrist 2: Male psychiatrist trained outside of Canada but with full registration as a psychiatrist in Canada; MD and FRCPC. Private practice and works with a psychosocial rehabilitation facility for the mentally ill.

Occupational Therapist: Female with experience in both hospital and community mental health settings. Currently working with the early psychosis program in a community mental health setting.

Registered Nurse: Female with long experience in community mental health. Currently employed as a nurse case manager with the chronic and persistently mentally ill in a community mental health setting.

Life Skills Worker: Female, teaches life skills at the community clubhouse.

Family Member: Female who was a teenager when her mother was first diagnosed.

Five professionals who work with the mentally ill were interviewed, along with one family member. The data produced by these interviews assist in corroborating the findings from the participant sample.

7.3 Conclusion

Chapter Seven has briefly introduced the demographical details of the participants in terms of gender, age, medications, housing, marital status, and religious affiliation. These demographics presented in a narrative form, give snapshots of the persons but with care to not reveal their identity. In addition, the demographics of the professional sample have been outlined for the reader. The participants, largely in middle age, eagerly took part in the research and demonstrated that a process to insight development does exist. Chapters Eight through to Thirteen now present the findings of the research. They begin with an introduction to the process of insight development

and a process map to guide the reader through the lengthy findings of the insight development process.

CHAPTER EIGHT PROCESS TO INSIGHT DEVELOPMENT

A PERIOD OF CHAOS

Preamble

> OT: … anyone that I have met with schizophrenia, insight is, is something that, if it is going to develop, takes time and is a process.
>
> The lack of awareness of being ill is not a ubiquitous, consistent, constant, or essential aspect of the illness. (Cernovsky et al., 2004)

There appears to be a process to insight development and recovery. Process is described as a "series of evolving sequences of action/interaction that occur over time and space, changing or sometimes remaining the same in response to the situation or context" (Strauss & Corbin, 1998, p. 165). Three sequences, steps, or stages propel a person with schizophrenia from the first prodromal indicators of the illness, through a series of difficult, but essential, undulating steps. Eventually, these steps evolve to a place where the person enters a *Period of Wisdom* and integration of the illness can take place. Permeating this process are *Four Phenomena of Influence*. These influences are dynamic phenomena that, like the swell and surge of a wave, have ebb and flow properties. The waves influence but do not interfere with the process.

An outline map is provided to guide the reader through the lengthy process of insight development described in this document. It is followed by a more detailed explanation of the process and the phenomena that influence the process.

There are three main periods within the *Process of Insight Development* and there are four phenomena that influence this process. Additional elements and sub-processes

occur within the *Process of Insight Development.* The following map (Table 2) has been designed to navigate the reader through the process.

Table 2: Process of Insight Development Map

PROCESS OF INSIGHT DEVELOPMENT MAP		
THE PERIOD OF CHAOS	**THE DYNAMIC PERIOD: C.L.A.R.I.T.Y.**	**THE PERIOD OF WISDOM**
Indicating Possible Onset Breaking for the First Time Being Diagnosed 1. Denying the Illness 2. Explaining the Denial 3. Lacking Understanding Not Adhering 1. Learning the Hard Way 2. Acknowledging the Cycles Turning Point: **THE TRINITY OF CRISIS** 1. Event 2. Construction 3. Hearing a Connection **Paradox of Insight Development**	**C**ontrol and **C**reating Stable Supports 1. Housing, Money, and Life Skills 2. Establishing Supports i. Family ii. Physician iii. Case Manager iv. Peer Support v. Friendship **L**earning about the Illness **A**ccepting Feedback 1. Feedback from Others 2. Integrating the Feedback **R**ight Medication **Four Types of I**nsight 1. Introspective Insight 2. Retrospective Insight 3. Interpersonal Insight 4. Strategic Insight i. Self-talk/Pushing Self ii. Maintaining Stability **T**reatment Importance 1. Importance and Positive Influence of Medication 2. Strategies for Fidelity **Y**ielding to the Illness	Talking about the Illness 1. Telling My Story 2. Acknowledging My Strengths and Values 3. Giving Advice Finding Meaning and Purpose Integrating the Illness Sustaining the Wellness **Four Phenomena of Influence** 1. Losses 2. Barriers i. Barrier of Social Construction ii. Barrier of Others' Expectations iii. Barrier of Poverty 3. Relationships (Professional Supports) i. Physician: therapeutic alliance, clinical, communication and empowerment ii. Case Manager: clinical, education, practice, social, emotional, and vocational 4. God i. Relying on God ii. Comfort/Safety iii. Partnership iv. Balancing Religion

8.1 Introduction to the Period of Chaos

> Chaos: utter confusion and disorder, confused mass or mixture, without order or connections. (*Oxford English Dictionary*, 1985, p. 379)

This chapter now describes the first part of the insight process, the *Period of Chaos*. The *Period of Chaos* begins with the prodromal features, the first break, diagnosis, and the process of denying the illness. Participants in this study explained the denial and how they learnt the hard way before there was an event that marked the turning point of the illness.

Ko, Yeh, Hsu, Chung, and Yen (2006) report that they are not aware of any study that has explored the processes of insight formation among patients with schizophrenia. From their own study, they note that insight formation is an "active process" in which patients with schizophrenia "gain knowledge about their medication, connect the association between their medication and symptoms and realize they need to deal with issues" (p. 124). An active process of insight development was revealed in this current study on insight in schizophrenia and is featured in Chapters Eight, Nine, Ten, and Eleven. People in the study vividly described a chaotic, tumultuous, and confusing period in their lives. This chaotic period had subtle beginnings with prodromal symptoms, but following the first break from reality, the chaos rapidly increased. A culminating event formed a turning point that ended the *Period of Chaos*.

8.2 Indicating Possible Onset

> Irene: I was showing signs of my illness back when I was 17 to 18 years old. … When I look back I can see myself slowly stepping towards the diagnosis of schizophrenia or something. … Oh yeah, I knew something was wrong … I knew this isn't normal for me. But I really never knew what was going on.

> Like I knew it wasn't normal, but I didn't tell mom because I thought, well, maybe it's just a teenage thing.

Prodromal features are a subject of interest in schizophrenia research as they contain clues foretelling onset of the illness. Prodromal symptoms of schizophrenia include disturbances of perceptions, beliefs, cognition, affect, and behaviour (Perkins et al., 2000). Participants spoke of painful childhoods, swirling with difficult psychosocial family dynamics, and their symptoms, such as bizarre behaviours, mood disturbances, personality traits, and social dysfunction. Family issues cited were multigenerational abuse, parents "scarred by war", parents ill equipped for parenting, parental rejection, death of a parent, and family history of mental illness/substance abuse. Behaviours included screaming at teachers, being in trouble as a child, transience/homelessness and assaulting others:

> Carol: I was charged with assault one time, before the rape at the university. I was bumming smokes and had no place to live at the time, and was just going from … place to place.

People reported anger, crying and depression indicative of mood instability. As well, personality features were reported: sensitive, clingy, hypochondriac, and lacking a sense of humour. Zack thought himself an "odd duck". Socially, people acknowledged they had been bullied, abused, raped, had abused substances, and had poor boundaries. Feelings of social ineptness pervaded their childhood and adolescent peer relationships:

> Yvette: … I never had friends when I grew up, I didn't have boyfriends and dates. … I seem to have a hard time making friends.

> Owen: … I guess the reason I got sick is when I was in high school and I got picked on quite a bit, and a lot of the students I knew there didn't really treat me very well. … I was getting upset all the time … but I didn't have a lot of friends. … I felt like I was going to get ridiculed.

Awareness of these difficulties existed but was suppressed for fear of the consequences of telling. Lack of understanding about the aetiology of the symptoms also resulted in participants hiding their symptoms:

> Peter: … ah, I knew that I was going through something, but I didn't really see it as an illness, you know.
>
> Ingrid: … in my twenties, I was a real hypochondriac and I always had some ailment or something was wrong or whatever.

Embarrassment prevented Randy from help seeking after his first identified break:

> Well, I had sort of symptoms of schizophrenia when I was a teenager. … I was embarrassed to ask anybody. … It slowly progressed over time, more and more bigger, louder, ah, the seeing things, and stuff like that, and I was so scared, I didn't know what to do.

Elly unwittingly layered drug use onto her prodromal symptoms:

> … if I knew I would be unleashing something like this by smoking a hash joint, I never would have smoked the joint.

Prodromal symptoms such as anxiety, depression, and stressful life events may lead to the development of schizophrenia (Rueter, Scaramella, Wallace, & Conger, 1999). Campbell and Morrison (2007) report that all participants in their study had experienced anxiety and believed that negative life experiences had influenced their paranoid ideas. The relationship between childhood trauma, loss, stress, psychosis, and societal and familial dysfunction, abuse and trauma is an important precursor to psychotic disorders (Read, Mosher, & Bentall, 2004). Resnick et al. (2003) note a positive association between trauma, PTSD, and schizophrenia. While substance use might also be a risk factor for schizophrenia (Barnes & Mutsatsa, 2006), indicators such as thought interference, disturbances of receptive language, or visual distortions are predictive of schizophrenia (Klosterkotter, Hellmich, Steinmeyerm, & Schultze-Lutter, 2001). Both genetic and psychosocial risk factors play a role in the prodromal period, and while these factors may not "cause" the illness, they are "more or less

important boosting factor(s)" (Cullberg, 2003, p. 209). Whatever the aetiology, prodromal symptoms foretell the chaos of the illness and herald the first break from reality. "First break" is a term used in psychiatry to depict the first episode of psychosis.

8.3 Breaking for the First Time

Stress impacted the first break for the people in this study. Stress added to the prodromal features, "where there is smoke there is fire", igniting a full-blown illness that manifested symptoms:

> FM: … there was a stress level … that was so astronomical that it was probably what triggered my mom's break. … I was in and out of court cases. … My step-dad was abusive. … It all came out, my mom, at the same time had her break.
>
> Norm: Uh, actually one of my first jobs. … I was really struggling with stress at that time. … It started off … fine (but) after working for a while and getting involved with the people, I noticed myself, uh, getting paranoid …
>
> Patty: A whole bunch, and my dad died, and yeah. My dad died and just it all, just piled up.

As discussed in Chapter Two, people with genetic risk of schizophrenia are less able to tolerate stressful situations (Leung & Chue, 2000; Phillips, Francey, Edwards, & McMurray, 2007; Rudnick, 2001). Encountering stress, given their stress vulnerability, can activate the illness.

The first break hosted a myriad of positive symptoms: tactile, olfactory, and visual hallucinations, delusional beliefs, voices, thought broadcasting, ideas of reference, and paranoia:

> Elly: … I'd look at a fire. … We'd have a fire burning logs in the cabin that we were staying in … I'd see … war, um, action video kind of. The wood would turn into people and they were fighting with swords, um smells, different smells of my olfactory senses were heightened … hearing not voices, more like an echo in my head like some of the wires were short crossing, right?

Additionally, negative symptoms were intensified. Olive described sleep disturbances, "… all I could do was sleep all day and all night, you know, so that I didn't notice the symptoms or anything." Other negative symptoms were evident: isolation, mood symptoms, panic attacks, fear of crowds, guilt, anxiety, and lack of self-care were reported. Carl said, "You have trouble keeping yourself clean, you don't keep care of yourself." Positive and negative symptoms prevailed during their first break from reality. Participants reported overwhelming symptom intensity that was hard to sort out, was persuasive, troubling, disturbing, and terrifying. Engulfed by the psychosis, they responded to the symptoms and completely lost time, lost insight, and lost awareness:

> Randy: … the voices seem like they are just right beside you and right there, talking to you. … I get very paranoid; I am very suspicious of people. … When people look at me, when I am walking down the street or wherever it is, I think they are plotting something to kill me … and the voices will tell me that.

Clearly, psychosis is a qualitatively different experience of life from what most people experience. The onset of bizarre beliefs and behaviour, mood instability, and ensuing concern of family and friends provoked contact with medical professionals who subsequently diagnosed the condition.

8.4 Being Diagnosed

Insight at the time of first hospitalization was nearly non-existent. Insight did not develop during the first hospitalization. Despite hearing a diagnosis, Ingrid disbelieved, "I think it was a long time, though, before I really believed that I had schizophrenia." That Yvette flatly refused to listen is a symptom of her disbelief:

> At one time, I would not allow him or anybody else to even say the word schizophrenia. I would stop that. To me that was like a killer, it was the most awful thing you could hang on a person.

Others claimed they were not told of their diagnosis:

> FM: They never really gave her a diagnosis, they just told her, Take this medication, and they didn't explain to her why she needed to stay on it or anything.
>
> Ingrid: … I was standing at the nurses' station and I looked at my chart and it said, Acute schizophrenia. Well, I was just devastated. I thought, Oh, my God. I phoned (my husband) and I said, Have they said anything to you about having schizophrenia? And he said, No. Well, it says that on my chart.

Others remained ambivalent as to whether they had actually been sick with schizophrenia. Diagnostic ambivalence existed:

> Sam: … you're not sure whether you're sick or you're not sick. And you're asking yourself, Am I sick? All the time. I may not feel sick, and you are … mentally … ill …
>
> Olive: No, even though I was diagnosed … I didn't know that I was schizophrenic, I thought it was just my panic attacks … making me crazy and um, having these voices. … I swore I was having a heart (attack). … The label of schizophrenia was foreign to me. … There was a lot of shame involved so it was really never pursued.

There may be some reason for the ambiguity surrounding diagnosis, at least initially. Lobel et al. (1992) report that acute psychosis *could* reflect an active morbid process. In addition, first episode psychosis is not a feature that belongs solely to the realm of schizophrenia as psychosis can indicate mood disorders such as bipolar or psychotic depression. Physicians often take a "wait and see" approach before offering a diagnosis:

> The screening instruments currently available are inadequate for the accurate prediction of psychosis, and the risks of negative effects for the large numbers of people who screen false positive are considerable. These risks include unnecessary fear of illness, restriction of life goals, use of medication and their side-effects. (Warner, 2005, pp. 104-107)

This wait and see approach by physicians may be necessary to clarify the diagnosis, but certainly explains why significant ambivalence about "what they have" exists for people who are later diagnosed with schizophrenia.

8.5 Denying the Illness

> OT: … it is just human nature to question when somebody tells us big and scary (news). … So for a lot of young people who are told that they may have this illness, and they may or may not believe it or agree to some extent.

Denial is a well-documented trait in schizophrenia (Arduini et al., 2003; McGorry & McConville, 1999). In this study, participants offered explanations for their denial, such as stigma, and for their innocence and ignorance about the overwhelming power of the disease.

8.5.1 Explaining the Denial

> Zack: There is quite a few people with schizophrenia, and they don't know they are schizophrenic, they have no clue that they're schizophrenic, I know.

Several reasons exist for people in the study to want to deny their illness. While partial insight may have existed, denial defends against both the stigma of a mental illness and the grief associated with the loss of the potential of self.

Ingrid's narrative indicates some partial awareness:

> I think it was more other people than myself … believing that there was something wrong. … I knew something was wrong. It was almost like I was in a maze that I didn't know how to get out of.

Another illustration of partial insight is this statement by the life skills worker:

> We ask them if they have a diagnosis of mental illness and sometimes they will say to me that they are not sure, or they don't know.

Denial is exacerbated by the stigmatizing effect of the illness:

> Hannah: Ya, people would rather … be a street person, like talking to themselves at top volume, than go to see a psychiatrist because they are so afraid of the stigma. But they don't realize they have already got it.

Patients are more motivated to see a symptom as a stress symptom, and have a "stronger aversion" (Wong, Chui, Mok, Wong, & Chen, 2006, p. 433) to classifying a symptom as a psychotic symptom. This is called "motivated denial" and is used to cope with the "sting" (p. 434) of the illness. Denial is a protective adaptive strategy that while maintaining positive core beliefs about self and promoting self-esteem, has maladaptive effects on functioning (Cooke, Peters, Greenwood et al., 2007).

Not wanting to be different is another aspect of stigmatization that reinforces the denial:

> Art: I don't know. I just didn't want to accept that I had an illness, because I did well in school, sports, and I didn't want to feel different.
>
> Irene: I guess I want to believe that I will be okay. … I sometimes believe that I don't need my meds … to convince other people that I am not mentally ill. … I just want to be well without it.

Families are also stigmatized by the illness and reinforce the denial. Ingrid described a tirade with her father:

> I lit into him, and did I give it to him. I said, You are ashamed of me … you never came near me when I was sick, and you don't like to admit that I have had a mental illness, cause it reflects on you.

Olive also believed her parents were implicit in the denial: "No, no, I think my parents were in denial that one of their kids was gimped up, right?"

Grief and loss are associated with denial. Henry described how his life unravelled, "Um, I don't know, you don't really count on your life falling apart." Irene grieved her lost potential:

> I would have been different person, good nice person with a good job and, um, helping other people more, and that.

Denial may, in part, be due to anosognosia but it is preserved by stigma, family stigma, and the need to not be different from peers. As well, it may be used to ward off pending grief and loss of the potential of self. Denial may be a defence mechanism to hold back the realization of the cruel, pitiless power and permanence of the illness. While participants admitted denial was an aspect of denying the illness, they also revealed they did not understand the power and tenacity of the illness.

8.5.2 Lacking Understanding

> … patients who are less knowledgeable about their illness have poorer insight. (Wong et al., 2006, p. 428)

Participants spoke of not understanding the seriousness of the diagnosis, the enduring chronicity of the illness, or its impact on the rest of their lives. In this early period, people with schizophrenia are not necessarily motivated to deny their symptoms, but may lack knowledge of their symptoms (Johnson & Orrell, 1995). Olive's statement about her current insight conversely pointed to her earlier lack of knowledge and awareness of her symptoms:

> Researcher: Do you know when that is happening?
> Olive: *Now* I do.

People thought the disease would wear off, go away and disappear:

> Carl: I kept insisting that the disease would go away, but it never did. … Got the injections, I hear no voices for a long time, so I thought, maybe my disease is over and there is nothing there anymore.

> Zack: I probably didn't understand it back then. I knew I had problems, but I probably didn't understand it back then. It's taken me a while to learn and understand things.

People believed they were "cured" of the illness:

> Hannah: Yes, because I figured I was cured, the first time I went off medication, was when I was 19. I went off medication, and, ah, I did very well for a little time, but four years later, bang, I had a big nasty episode.

> Ingrid: I told Dr Z., I don't need this stuff anymore, and … well, a few months later, I was in the hospital again.
>
> Randy: I stopped taking it for a couple of days, I don't need to take it, I feel a lot better and it came on, slowly came on the loudness of the voices, the hallucinations and the paranoia.

Professionals are not surprised by this belief that they had been cured:

> OT: … people wanting to test out what it is. I think it's licked, I think I am cured, it is all gone, I've felt great for a few months, I am going off my medications. … It is a questioning … it would be natural for people to want to be sure to test things out.

Many patients recovering from a first psychotic episode will discontinue treatment, against medical advice, due to beliefs about severity of illness, need for treatment, and side effects of the medication (Perkins, Gu, Boteva, & Lieberman, 2005). People admit they lack understanding of the illness which leads to not adhering to their treatment plan.

8.6 Not Adhering

This time of denial and lack of understanding includes a rather lengthy period of not adhering to a treatment program. Turbulence, confusion, and chaos describe this messy and painful process that can carry serious consequences such as homelessness, prison, and repeated hospitalizations. However, people strongly believed the chaos of "learning the hard way" and "acknowledging the cycles" forced their insight through eventual recognition of the destructive cycles and patterns. The recognition of these patterns pre-empted change and wellness.

8.6.1 Learning the Hard Way

> Psychiatrist 2: How hard must someone's life be before they get it?

Carl, a 65-year-old man who had in excess of fifteen hospitalizations, told his story about learning the hard way:

> I thought maybe, when I took the medication the voices went away, I thought maybe I don't need the medication anymore, so I stopped taking it. I learned the hard way that it wears off. … I kept insisting that the disease would go away, but it never did. I was hard-headed. I stopped taking my medication and I learned the hard way that you can't stop taking it. … It took a lot of hard knocks …

Randy referred to his life as chaos when he was non adherent to treatment:

> It is chaos you know … it doesn't take very long before it gets bad … yes, that deep hole and the, that, the emptiness and the hopelessness is, is the worst feeling you could ever have, the way I see it, and I don't want to fall into that.

Irene remembered the pain of learning the hard way, "I know what it is like to get sick and the pain and the agony that it causes while you are sick." Elly talked about her own experiential learning:

> Staying on the right medication has been easy in comparison to the times when I have been off my medication and gone down the other road and fallen off the wagon, so to say.

Zack spoke of his rebellion in his early years: "… when I was younger, when I was more rebellious." A family member reported the pain of watching her mother learn the hard way and the resulting loss: "This is a woman, who literally lost 10 years of her life because she was in and out of psychosis, more times than not."

Hannah and Ingrid reported their mistakes and advised against nonadherence. Hannah noted that she had to learn about the importance of this for herself, but both she and Ingrid expressed the hope that others could learn from their mistakes:

> Hannah: I would say if you take your medication, good things will come of it. If you don't take your medication; it's like trying to manage diabetes without your insulin. People gave me that and I had to learn it for myself. So don't make the mistakes I did and go off your medication and end up in the dumps … I had to go through it myself to realize this is not good.

> Ingrid: I see people that have just been diagnosed with a mental illness and I wished I could tell them, don't make the mistakes I did … mistakes … not taking your medication, mistakes …

Elly expressed a ruefulness that she had to experience such painful learning. She was optimistic that people with schizophrenia can learn from the mistakes of others and thereby avoid the distressing setbacks that she experienced:

> I don't think anyone has to go to the hospital three times from trying to kill themselves … to learn that they had better stay on their medication or else. … I think if someone is diagnosed at the right time, at the right age and they get on the right medication, you can have a carefree life … or you're not getting the right help, yeah, you're going to have set backs. Um, if you're not helping yourself you're going to have set backs.

Cycles and patterns began to emerge in the awareness of the participants as they "learned the hard way". Learning the hard way also involved learning that side effects accompany treatment medications and most were unwilling to put up with the side effects. Hannah described her side effects as "horrendous", Carl reported, "Now, they caused me to get blood clot in my leg", while others spoke of the uncomfortable medication side effects that deterred them from medication adherence:

> Elly: I had put on 35 almost 40 pounds and I was very depressed and it was all I could do to get out of bed and get into the bath. I was almost to the point where I was incapacitated and so drugged that I could not feel anything, I had no emotions … no sort of motivation.

> Henry: I really didn't like the side effects of the old Stelazine and I slept, like, long days and feeling like I was better off with the sickness than living on the medication and sleeping.

> Olive: I really didn't like taking my pills when all they did was make me sleep all day and all night, right.

The FM reported her mother had significant side effects that provoked nonadherence:

> Haldol and it was giving her some pretty nasty symptoms. She was getting the tardive dyskinesia. … Her face would kind of go numb, the symptoms on the medication were kind of outweighing why she was on it for her, and so, I think she stopped taking her medications.

Professionals believed that side effects are often what cause medication infidelity:

> OT: I have met people who have had insight into their illness and stopped taking their meds, but not because they don't think they need them but because of the side effects are so nasty.

"Learning the hard way" included recognizing that treatment comes with consequences, and that on the other hand, the consequences of going off medication in order to ward off side effects creates patterns and cycles of relapse.

This "learning the hard way" may be evidence of compromised insight and lack of ability to "self-reflect, acknowledge the possibility of being mistaken, be open for feedback, and to refrain from overconfidence" (Beck et al., 2004, p. 325). The neurocognitive brain dysfunction well cited in literature (Donohue et al., 2005; Velligan, Kern, & Gold, 2006) may be responsible for this phenomenon of learning the hard way and may delay the revelation of patterns and their consequences to the person with the illness:

> In essence, standard environmental cues do not appear to reliably activate the effort of patients, and many fail to adjust their performance in the face of changing contingencies. Similarly, the experience of success, and of failure, often does not lead to behavioural adaptation as one might expect in a non-ill group. (Velligan et al., 2006, p. 481)

Authorities note the disturbances in both neurocognitive test performance and clinical behaviour in people with the illness, indicating compromised ability to self-correct (using feedback to correct past mistakes and guide subsequent behaviour) (Kern et al., 2005). Hypothesis generation from environmental data results in impaired problem solving in people with schizophrenia (Thomas, Dougherty, Sprenger, & Harbison, 2008). This may be because people with schizophrenia have difficulty recalling specific past events and projecting future episodes (D'Argembeau, Raffard, & Van der Linden, 2008). Therefore, it may take longer for people with schizophrenia to build memory in order to project and take charge of their future. If motivational

deficits in schizophrenia represent problems in the ability to translate experience into action (Heerey & Gold, 2007), then experiential "learning the hard way" is the mnemonic tool to translate experience into the action of change and recovery.

8.6.2 Acknowledging the Cycles

> Psychiatrist 2: We also learn through patterns of successes and we learn through patterns of failures.

Mentally ill populations are characterized by repeated cycles of hospitalization caused by psychotic episodes (Roe & Chopra, 2003) and these cycles and patterns seep into the awareness of people with the illness. The cycles reflect sick/not sick; on medication/off medication; wellness/relapse; out of hospital/in hospital; pattern of brain damage/longer recovery, as well as cycles of addiction.

Owen reported that others saw the "patterns" in his life: "They saw the patterns, saw the patterns and they knew this guy has a problem … getting mad … I just wanted to hurt people." Others also noted their cycles and patterns:

> Carl: If you are not sick anymore, it is because you have been on medication for a while, but as soon as you stop taking it, start skipping, you will eventually get sick again, and you will realize that schizophrenia is with you for a whole lifetime, there is no cure. … If they start skipping their medication they will be back in hospital a second time … a hundred times.

> Hannah: … if you go on it and off it and on it and off it, and that is how people get into the revolving door syndrome, if they don't take their medication. I didn't at first, I didn't at second, but by gum, I got it the third time (laughs).

> Norm: I hit bottom and started up again … Um, well, you know, there is probably a few times when I hit bottom, but you know, it's uh, a type of thing that you know, I ain't quit yet.

Art spoke of how his cycles of trying to work, volunteer, go to school and manage his sobriety resulted in relapses and hospitalization:

> I had to pay attention to how much I was doing, because *the last few times* I was institutionalized, I was doing too much. … I was working full time, I was going to school part time, and I was very active in the 12-step program doing service, and I just had a nervous breakdown.

Carl identified cycles of being able to work and not being able to work, living with his mother, not living with his mother, family supporting him, family angry with him:

> You try working, sometimes you don't work, sometimes you can … keep quitting jobs and getting other jobs and quitting 'em and getting another one. My family tried to help me; they were forever trying to get me … to keep on working and to, ah, not live off my mother. … I'd get a job, hold it for a couple of months and then I was so sick, I would quit it, and then they would scream at me to get a job.

Henry and Ingrid described their cycles:

> Henry: because, if I didn't take it I would be hospitalized. … I didn't want to take them and I would take them for a while and then go off and they would put me back in the hospital.
>
> Ingrid: … don't think that you are so smart that you know that you don't need this anymore, don't ever say, I don't need this. I don't know how many times I've heard of people saying this, I don't need this stuff. … Well, a few months later, I was in the hospital again, so if you want to relapse, go ahead, go off your meds, but you will be sorry that you did.

Substance abuse is a well researched, underlying factor in not adhering to treatment (Drake & Wallach, 2000). Patterns of abusing substances were identified as people began to recognize that substance abuse cycled into relapse:

> Art: I started mixing them, when I first got diagnosed, I wasn't using drugs and then I started mixing Chlorpromazine with alcohol and marijuana and LSD, and I found that those drugs gave me relief. … And then after about two years of that, I ended up getting sick and then I ended up on the psych ward for, ah, eight months, a long stay.

Carol noted that many of her cycles of hospitalization were associated with substance abuse:

> My hospitalizations were complicated, because I was mostly in for treatment for alcohol abuse. I first went to treatment at 21-22 years of age. I was about half way through university and I was drinking and partying a lot.

Carl described his substance abuse as a "vicious circle":

> Now, if you spend all your money on tobacco and if you drink beer, most schizophrenics are young, the young have sexual problems, and if you are schizophrenic with sexual problems, you go out and get drunk and watch the strippers and spend all your money, and then you will be dirty again and a bum and you won't keep care of yourself, you won't be able to, and then you will get sick again. It is a vicious circle, a vicious circle.

Elly began to recognize how her genetic vulnerability for substance abuse created cycles of psychosis:

> … as opposed to getting stuck in a cycle of, of, you know, sort of you're taking yourself away from that path and it is so easy to get deterred. Um, I could have inherited a gene from my father's side of the family, that the drugs, maybe, this is why everyone who smokes hash doesn't have schizophrenia and I do.

Yvette reported cycles of suicidal ideation when she drank:

> … when I drink, I become suicidal. … I do cry a lot when I am drinking and, um, I am inclined to be suicidal, like, I should say, I would kill myself, but no, I wouldn't, but I mean I would not care.

The RN confirmed that clients with the illness do recognize the patterns and cycles and this recognition can provide a window for change:

> They actually can see a pattern that they want to, somehow, want to break and change. … They are sick … they are compliant, they are stabilized in hospital, and then, they start feeling well again. … They think, Ok, I am sick, I will take my pills. But they feel well again and then, so they go off their pills and they have to realize that they are sick again, and they, eventually, somewhere in that cycle, they identify a spot that they themselves can make a change.

These cycles are propelled by ambivalence and the avoidance of the invidious decision that must be made. The double bind is explained:

> If the persons accept their diagnosis of having a chronic, severe mental illness with a generally poor outcome, their loss of hope is obviously justified. However, if they deny their illness, this denial is considered a disabling

> consequence of the illness, which is again evidence that they are ill and without hope. (Hasson-Ohayon, Kravtz, Roe, David, & Weisner, 2006, p. 268)

Simon, Berger, Giacomini, Ferrero, and Mohr (2006) agree this very difficult decision is critical. Patients must overcome the denial process and "admit to the wider impact of suffering from schizophrenia" (p. 447). Carl warned that delaying the decision to accept the illness and to be treatment compliant comes with a high price. A nasty event is inevitable:

> That's a chance you are taking if you are a schizophrenic and you are hearing voices and you are off your medication, that's what happens. You start screaming at people, and people say, What are you screaming about, weirdo, and they start beating you up. Now, if you don't want to get beaten up, or put in prison, if you don't want to take a knife and stab somebody, if you don't want to do all those things, then you take your medication. Eventually, you will hurt someone or someone will hurt you. If you go up to people and you are nasty, because you think they are talking about you and you are hearing voices, people will be nasty with you, and they will attack you if you are not careful.

This nasty event to which Carl was referring is the turning point from acute illness to a long path of recovery. While some of the literature speaks of a sense of hope necessary for recovery (Bonney & Stickley, 2008; Davidson et al., 2001; Deegan, 1994; Ridgway, 2001), hope is a process of acceptance of loss, accompanied by struggle, pain, and adversity (Jacoby, 1989). Chaos and despair, if teamed with an emerging realization of patterns and cycles, engender hope. Hope and potentiality can happen, "following a moment of utter despair-hitting rock bottom and deciding that forward is the only way to move" (Onken, Craig, Ralph, & Cook, 2007, p. 13). Hope is the "protective defenses they build against annihilation by the illness" (Haghighat, 2007, p. 189). Again, hope is the defence mechanism engendered by the painful cycles preceding a *Trinity of Crisis* (event, decision, and hearing a connective message) or turning point and the *Trinity of Crisis* is where the meaning making of dangerousness and, paradoxically, hope, is formed.

The efficacy of experiential learning is evident in this study. Some participants in Laithwaite's (2007) study also found that the nature of past experiences and how they contexualized their problems impacted their recovery. Experiential learning and development of awareness has a positive impact on the reality testing of people with schizophrenia (Serok, 1984) and assists in inducing critical decisions that play a role in their recovery (Chadwick, 2007).

Healthy people have the ability to consciously recollect the emotional context of a past event, thus guiding effective behaviour. People with schizophrenia are impaired in this ability and, in fact, exhibit poor recognition of the emotional valence of pictures that depict negative events (Neumann, Phillippot, & Danion, 2007). Therefore, repetition may be required to remember negative events and to guide behaviour. The repetition that emerges from the chaos produces patterns and the relevation of these patterns engenders hope and sets the stage for a turning point in the recovery process.

8.7 Turning Point (Trinity of Crisis)

> Psychiatrist 2: I think that often when features that people … uncomfortable for them to be in that state, that is often the biggest motivator of changing. … That can be a big drive force toward insight.

The notion of a "turning point" at which an option for making change presents itself is strongly evidenced by the data. This turning point embodies a *Trinity of Crisis*: 1) an event, 2) a (cognitive) construction, and 3), hearing a connection. First, the turning point occurs after a significant event that provokes such intense and sufficient discomfort and danger that breaks the cycles of ambivalence. Significantly, these

events appear to threaten physical and emotional safety. The second dynamic following this event is an invidious but firm decision to manage the illness, regardless of fears of not being normal, of the stigma and/or of the side effects. This decision is a meaning making or cognitive construction provoked by the dangerousness or seriousness of the event. Converging on this event and this cognitive construction to manage the illness is the third dynamic: the delivery of a timely message by a professional. This timely message, although often heard before, now makes sense to the person, and they are able to make a connection or a link between the illness and management of the illness. Delivery of this message occurs precisely at a time when vulnerability and receptivity to change is radically elevated. The trauma of the event is like an ice pick that painfully cracks and weakens the resistance to change and, in its brokenness, the resistance permits the "hearing" of a message that resonates, rings true, and makes sense.

8.7.1 Event

> Hannah: Sometimes fear is a good motivator.

Participants shared their turning points. These included being lost in the forest, running around barefoot in the snow, not feeling safe in their own home, severe depression, hospitalization, arrest, fear of dying, fear of suicide, death of a parent, stopping substance abuse, and extreme loneliness:

> Carol: That night I got lost in the forest, running all over the place, that event kind of gave me a jolt. I could have died that night, and I made a decision to never run away again. I guess it was a turning point, as I put myself into hospital. Once you reach that point, you do whatever it takes to keep yourself safe. … I was so scared, so frustrated. How did I get myself into this situation? I didn't want to kill myself. I have a family to live for. I have lots to live for yet.

The FM reported the dangerousness that was the turning point for her mother:

> I got a phone call from some friends of hers. … The dogs were all running around the yard, the front door was wide open, snow on the ground and her boots were still in the house and there was footprints out into the snow, bare footprints, and my mom was found wandering down the highway without any shoes or coat on in November. … So I gathered her up … and we just dropped her off at the police station and said that she was an endangerment to herself.

Others reported apprehensions of other dangers:

> Henry: Having a point in my life where I did not feel safe in my own home because of being off medication.
>
> Olive: Ya, I didn't want to sleep any more. I was so depressed that all I did was sleep. I just wanted to sleep my life away and I thought, NOO, you know, I can't let this happen.
>
> Peter: I would go off medication all the time and then they just threw me in the hospital until I finally said, well, geez. I even got arrested a few times, mental health arrest because I just didn't want to go to hospital. And I thought well, I may as well just take the medication and deal with my stupidity later.

Olive's turning point came after a suicide attempt:

> I took the whole wad and my roommate called the ambulance and went into hospital and that's when it came.

Owen's turning point occurred when he feared he would actually act out his homicidal thoughts: "I was plotting to kill people in the mall and at hockey games." Frightened he might act out his thoughts, hurt someone, be arrested and go to jail incited his adherence to medication.

Sarah's turning point was commitment to a psychiatric hospital:

> I had to hit rock bottom before I began to manage it … I hit bottom about 10-12 years ago when I was 17, I was in Riverview … oh, you know what happened? I smashed a window and they threw me into the hospital … the biggest thing that helped me turn the corner.

Danger was the turning point for Hannah:

> That was in 1996. … This is real, the illness is real, and that, that if I wanted to be able to live independently, I was going to have to manage it, micromanage it taking my pills every time I was supposed to, and I was going to have to put up with the side effects for the rest of my life because it was just getting too dangerous for me to have episodes.

Randy's mother died and he made a suicide attempt. He realized he needed to "grow up":

> I drove through a town and rented a motel and I put the no disturb sign on my door, and I think I took 30 Valium and I drank a bottle of vodka and I laid down and I said goodbye to everybody. … I'd wind up dead and that is one of the choices I have, you deal with it and you live and go on the best way you can or you can go ahead and commit suicide. … My mom died and, um, that was really hard, I had to really grow up. … My mom would do absolutely everything for me and it would never give me a chance. … The doctors would tell her, to leave him alone and let him do his thing and let him grow up. It never really changed until my mom died, and that is really when an eye opener, hey, I have to grow up here … do it for myself now. … I didn't want to die …

Irene also grew up when her mother died:

> I stayed on my meds because I didn't have my mom to help me if I got … sick … growing up and taking care of yourself, right?

Randy and Irene's narratives support the conceptual shifts in family systems psychiatry where there is now recognition that choice and empowerment for the person with the illness fosters ability for self-advocacy and self-determination in treatment planning (Schweitzer, Zwack, Weber, Nicolai, & Hirschenberger, 2007). This new model of family systems psychiatry shifts from families "doing for" and "doing as I say" to a model that is full of negotiation, discussion, participative planning, and choice, thus promoting self-efficacy and independence.

Olive summarized her turning point event and offered hope to people with schizophrenia:

> I think anybody can do it … because when you have had enough whether it is smoking cigarettes, drinking, or being in an abusive relationship with a husband, and that. When you have had enough, you make your mind up and you get out of there and you make changes … people change, you know.

8.7.2 Construction

Embedded in the event that provoked the turning point, there was a clear decision and cognitive construction process involved in change. Olive said, "… you make your mind up." Randy and Irene said they *decided* to grow up. Hannah decided to "micromanage" her illness. Many participants reported having abused alcohol in the past. Therefore, many turning points were synonymous with the decision to quit drinking after an event that produced discomfort or threatened danger. Yvette's turning point was provoked by her extreme loneliness. She quit drinking:

> Researcher: Was there a turning point for you?
> Yvette: I think so, when I quit drinking.

Carol stopped drinking when her safety was threatened:

> So I went out to a bar and got drunk, and a man came by and drove me up to Toronto and he wanted to sleep with me, and I said, no. But he had a temper and he raped me, then he got up and hit me with his car. He broke my leg with the car and took off. I had to flag someone down and they took me to hospital.

Despite a relapse, it was again an event that threatened Carol's safety that led her to renew her decision to stop drinking and manage her illness:

> I thought that I was missing out on partying, and so I got involved with people who were drinking. I got all fuzzy and began partying. I became very unreasonable – my judgement was not very good at that time. I ran away. I ran into the woods and got lost. I lost my shoe. I had one shoe off and one shoe on. I stayed up all night trying to find a road out of the woods. I eventually did find a road, and a car drove up. I checked myself into hospital that time for one month. Once you reach that point, you do whatever it takes to keep yourself safe. … I don't drink alcohol now.

Substance abuse coupled with schizophrenia has poor recovery outcomes (Pencer & Addington, 2003), and yet when people involve themselves in treatment, they increase in recovery measures such as life satisfaction, better illness control, increased social contact with non-substance abusing friends and increased competitive work abilities (Xie, McHugo, Helmstetter, & Drake, 2004).

"Hitting bottom" provoked Olive's decision to change, "I was at that point where I wanted to change, I didn't want to be on the bottom any more because once you hit rock bottom, the only way is up, right?"

8.7.3 Hearing a Connection

> LSW: … other people say it is just something I heard, one phrase the case manager or doctor says that twigs them.

Converging on the event and the decision to manage the illness is a word, phrase, or prescriptive instruction that makes sense to the person. Vulnerability created at the turning point event fostered a willingness or ability to hear the message and make a connection between the illness and the management of the illness. "What is also important is the patients' readiness to use such knowledge to grasp their illness experiences" (Wong, Chiu, Mok, Wong, & Chen, 2006, p. 434). Carl provided an example of this readiness:

> T. worked at the mental health unit. … She eventually (told me, You have) got to keep taking medication, you got to keep taking it. Now, S., my nurse now, told me the same thing; You got to keep taking it. I have been told so many times to take my medications that it finally sunk in (laughs). It finally sunk in how important it is … I was finally ready to hear it. ... In hospital, I was told that my dopamine levels were low and that I had a chemical imbalance. I take my pills. It makes sense.

Elly's frightening experience with psychosis following her drug abuse metaphorically opened her ears, "I know I have to take it. You have to understand that what Dr G. told me. I have a chemical imbalance. That seemed to make sense to me. I can accept that."

Olive's decision that she wanted a better life was followed by a message she heard from her case manager: "Ya, you just get fed up with life. I remember M. telling me years ago, the definition of insanity is doing the same thing over and over again and expecting a different result." Recovery followed this connection between the cycles of her life and management of her illness. Further examples illustrate this connective message:

> Hannah: Well, somebody, I think it was C. who said, Every time you talk about your mom you are getting upset and then you need to take a pill. … Ah, many people said that to me, it just sort of clicked in.
>
> Henry: But then, ah, one doctor once said to me, Oh, your thoughts are so much more organized now. So then that was, kind of, what started, at least being able to relate to what was being said. … He was like, You seem so much more organized. And I believed him. I think it had a meaning, right?
>
> Art: The nurses explained it, like, the medication forms a bubble to protect you, and the only thing that protects that bubble is the medication is helping it and the stress breaks the bubble.
>
> Peter: … another nurse said, Having a mental illness is just the same as having a physical illness, it is just totally different. And that has helped me understand it a little bit better.

Other messages included: "like diabetes, there is no cure, just control"; "we are all predisposed to something"; "diabetics have to live with the repercussions of their habits as well"; "it is just an injection and a couple of pills a day"; "it is your mental illness doing these things." The trigger to insight was a significant event that precipitated a decision to manage the illness and produced a vulnerability to listen to an intervening and "connective message" by a professional; this message made a connection between the illness and the management of the illness.

Hearing a connective message contains a second, important component. People in the study begged mental health professionals to continue to repeat these messages over

and over until it was heard. Art said, "The nurses kept reinforcing that 'it is your illness'. I needed to hear that over and over. It was like a bad nightmare, I actually believed my landlord was out to kill." This concept was reinforced by other participants:

> Randy: It is just being stressed over and over again by doctors and counsellors that I have to stay on my medication or I just get really sick and life goes right down and back in hospital.
>
> Sam: Um, you have to be told over and over and over again before you realize that you have an illness.

The RN saw efficacy in repeating these messages until heard:

> I just keep asking them and I draw things and I ask them, Does this look right? Does this look familiar, can you address it, can you tell me what you see? Can you tell me what you have noticed? And then just try to get them to see certain things for themselves. … I mean, sometimes, you have to deliver it differently.

8.8 Paradox of Insight Development

Coupled with knowledge about the illness, there must be a *readiness* to use this knowledge (Wong et al., 2006). People with schizophrenia exhibit a greater willingness toward an illness attribution for their state when they are anxious and considering someone else's predicament over their own (Saravanan et al., 2007). This gives credence to the importance of meaning making following an event that has made them anxious and where, as a result of their behaviours, they have posed risk to others. The dangerous event and the construction of dangerousness precipitate the motivation to receive and apply the message. The illness itself serves as a source of new understanding, that, even in the face of crisis or loss, innate potential for growth is often present (Roe & Chopra, 2003). This stumbling and tumbling during the *Period of Chaos* leads a person to recovery. This is called the *Paradox of Insight Development***.** It is this paradox that is, in a sense, the genesis of insight development.

8.9 Conclusion

Chapter Eight has described the first part of the insight process, the *Period of Chaos*. The *Period of Chaos* began with the prodromal features, the first break, diagnosis, and the process of denying the illness. Participants explained the impact of denial and how they learned the hard way that this actually provokes an event. "Learning the hard way" appears to actually be experiential learning that finally culminates in an event that marks the turning point of the illness. This event paired with a decision and hearing a connective message forms the *Trinity of Crisis* (event, decision, hearing a connection) and is the transition point where they leave behind the chaos and turmoil. This *Trinity of Crisis* is really the preparation stage that moves from denial, precontemplation and contemplation, to the action phase of change. This action phase of change is termed *The Dynamic Period*. This *Dynamic Period* is a period where the action of taking control of the illness produces *C.L.A.R.I.T.Y.* around insight. This *Dynamic Period* that produces insight *C.L.A.R.I.T.Y.* is the focus of Chapters Nine and Ten.

CHAPTER NINE THE DYNAMIC PERIOD

A PERIOD OF C.L.A.R.I.T.Y.

> These reported changes seemed to emerge out of a qualitative shift in the experience of self, from a less coherent, more passive sense of self, to a more integrated, dynamic sense that the self could function as an agent of meaning and change. (Roe & Chopra, 2003, p. 343)

9.1 Introduction

The *Dynamic Period* is the middle stage of the process of insight development. Here, people developed clarity by establishing stability and obtaining support people, learning about the illness, and being able to accept feedback from others. Additionally, they were finally placed on the right medication.

Once the lock is tumbled to insight by the chaos and the *Trinity of Crisis*, the person enters the *Dynamic Period*. This unlocking opens the door to clarity and insight. Hence the acronym *C.L.A.R.I.T.Y.* is used to outline the dynamic process. While not all participants' stories fully conformed to the *C.L.A.R.I.T.Y.* pathway, the majority of participants spoke about experiences that related to each aspect of the pathway, thus providing sufficient data to develop the pathway. The *Dynamic Period* is the time where the person takes control of their illness through the creation of stability which allows them the space and time to heal while actively learning about their illness, accepting feedback, and allowing regular support from a physician whose willingness to adjust their medication leads to the "right" medication. This combination of factors cultivates insight, whereby people can understand their symptoms are illness related, medication is recognized as important and valuable rather than cursed, and where a gentle yielding, submitting, and accepting of schizophrenia takes place. This chapter

elaborates on these findings and provides rich evidence for support. The dimensions of *C.L.A.R.I.T.Y.* are listed below for the reader. The first four dimensions are discussed in this chapter.

Control and Creating Stability
Learning about the Illness
Accepting Feedback
Right Medication
Insight Development
Treatment Importance
Yielding to the Illness

9.2 Control and Creating Stability

> Ingrid: … there are three types of people in this world, ones who makes things happen, ones who let life happen and ones who say, What happened? So I no longer want to be one of those who say, What happened? I want to be one of those that make life happen.

Once they have made a decision to manage their illness, people can take back the reins of control in their lives by fighting back from the hopelessness of the vicious cycles and patterns created in the *Period of Chaos*. Irene began to take control of her recovery management:

> I told him that I would never be sick again. … I just (was getting) to the point that I was tired of going to mental health every ten days for a shot, and I wanted to be more in control of my care, and I felt that I had come along enough that I could be trusted to take my meds. And so then they started me on pimozide and I have been on that ever since.

Art began to pay attention to what was being taught as a way to get control of his illness:

> … I started paying attention to the courses they were offering … about self-care, even though, intellectually, I knew it, but I wasn't doing it. … like proper sleep, proper food … and other things. I learned, um, to be honest about your symptoms.

Irene, Art, and Olive began to fight the illness to gain control:

> Irene: By pushing yourself to reach a goal or a limit, to go as far as you can.

> Art: I have to fight it. A good friend of mine, a psychiatric nurse, said, You have to fight your illness, don't let it beat you.
>
> Olive: I needed to take steps. I needed to learn coping skills, and need to not hide in (hospital) … because I like it there. … But I was told to "move on" and … get on with my life.

Taking control also seems to imply a taking of personal responsibility. This theme of taking responsibility is evidenced by several quotes from the data:

> Sam: You got to keep going, in such a way that you don't fall back on yourself. If you start blaming yourself, then you don't get anywhere. You can't blame others either.
>
> Yvette: I do have a fear of relapse … ended up back in hospital and I don't want to be there. I don't like it … treated like a child, you have no responsibility. … You are sick and we take care of you. And that is … the loss of control … scares me and I never want to be there … I don't like it.
>
> Zack: I just try to stay out of trouble. You should basically take care of certain things … but I often control the rest of it.
>
> Elly: Everything that has happened to me has made me what I am. Everything that I have done, so far in this lifetime, I'm completely responsible for and I'll take responsibility for it.
>
> Peter: … and don't expect others to solve your problem like I used to, and like, not take medications, or something.

Taking control of their illness involved creating stability for themselves by providing themselves with housing, money, and life skills and by establishing both an informal and formal support system for themselves. "Real choice is not possible, however, without the meaningful options ….the provision of such opportunities and tangible resources … social psychological, financial and material resources" (Onken et al., 2007, p. 16).

Deciding it is time to manage and control their illness in the *Period of Chaos* is followed by the creation of stability. Creating stability for the participants involved two sets of factors: housing, finances, and life skills, and establishing supports that

included family, physician, case manager (CM), peers and friendships. Creating stability begins the recovery period of the process and leaves behind the chaos of acute illness.

9.2.1 Housing, Money, and Life Skills

Carl credited a transition facility from acute care to community as his opportunity to begin his recovery process:

> K facility … I'm glad I had a place to go. I didn't know where to start. … I was given a chance, to start a life all over again. … She said, Hey, you got to eat, you got to spend your money on food, you got to spend your money on, on your, uh, rent, utilities. Don't spend it on anything else. To make sure you pay your bills.

The safe housing assistance and access to welfare funds and life skills support provided at K facility afforded this man, who had been transient, homeless, and hospitalized in excess of fifteen times, stability. Stability, lifeskills and money were important to people in the study:

> I lived in (a group home) for about 2.5 years and at first I really needed it because I basically couldn't do anything on my own. … I am functioning and making my dinners and having my showers and changing my clothes and washing my clothes, as before, I couldn't do that, I wasn't taking my medication on time. … It was a challenge and I learned more about my illness and that helps.
>
> Hannah: My address had to be moved to follow the cheap rent and this was not good for my health. It sort of caught up to me after a while.
>
> Researcher: So getting some housing stability was important?
>
> Hannah: Crucial. If you have no where to live and you are always living on somebody else's couch, you can't have the private space you need in order to sort yourself out and sort your mind out.
>
> Sarah: (Group home) … money. … It helps me because … I have a place to stay and makes sure that I am fed and clothed.

Many spoke of the relief and stability that a government disability pension (called PWD in British Columbia) provided:

> Olive: … when I was working … I was under a lot of stress. … Oh my God, I got to pay rent, got to get food, got to do this, and just your basic needs. … I got to work and I would get so stressed out that I would have panic attacks, but being on PWD was like, a, whew, now, I am going to have these basic needs met. … That was a blessing thing, to get on PWD.
>
> Henry: … and a perfect example is that if you look at PWD and it is hard to get on, and once you get on, they are not hounding you to death every month.

Hannah continued to have unstable housing until she received her disability benefit:

> Researcher: So you were losing your housing because of costs?
> Hannah: Costs, there was no subsidization until much later. …
> I am (now) on a provincial disability benefit.

Psychiatrist 2 also saw the value in providing resources up front to create stability where, "the issue is often housing".

Creation of stability through housing, finances, support, and life skills provided the person with security that, in turn, facilitated establishing the relational support necessary for insight development.

9.2.2 Establishing Stable Supports

> Although much of the struggle to seek change is an act of the solitary self, a supportive network, including formal and informal supports, can foster such a shift by pointing to or helping to create opportunities for change. (Onken et al., 2007, p. 13)
>
> Elly: There's support, don't be afraid to ask for help, let me know how you're feeling and don't be afraid, no one here is going to hurt you. … Just that total lift the curtain of darkness away and open up that little window of light there for them to see and start on their journey.

A man with schizophrenia speaking with an interviewer reported, "I'm nobody 'til somebody loves me. That's the way I look at it" (cited in Shahar et al., 2004, p. 480).

Relationship defined this man as it defines us all. Bassman (1997) reports, that, almost universally, those who are recovering from their experience of mental illness point to some individual who inspired hope by providing warmth and support. In his study, he speaks about the "extraordinary gift of human contact" (p. 241) that is provided by a person who is often deemed the one "who halts the downward slide and gives the necessary boost for one's upward climb" (p. 241). The people providing this extraordinary gift of human contact essential to insight development and recovery included the family, doctors, case managers, peers, and friends. A psychiatrist spoke of the need for relationships and provided discourse on dependency and interdependency:

> Psychiatrist 2: I personally feel that the word independence should be classified as a swear word, because we want our clients to be independent? But we do not look at the amount of dependent behaviour that we all exhibit. We are all part of a network … so, can you then classify us as dependent or independent? … One of the obstacles is rebuilding that social network and that is part of the social drift as you have relapses, as you keep on behaving oddly, people withdraw, first your acquaintances, and then the friends, then those that are further away, and then your close friends and your family, and eventually, all you have is your mother. And that is, that is one of the big problems, um, I think that no society can afford to pay people to do during a work week, what we all do after hours to our families and friends. … This is a labour of love, and that is what the individual needs, I think.

The OT agreed: "I think it is critical … having supportive and trusting people in their lives." Stability included the building of a relational support system for the person with the illness.

9.2.2.1 Physician

Family support is important to insight and recovery development but establishing stability also involves the family and the patient having access to a professional support team that includes a doctor and mental health worker. Participants valued their physicians for their knowledge, their willingness to negotiate and preserve

patient autonomy, their honesty, and their personal qualities. Randy's quote summarizes the virtues he cherished in his physician:

> … his explanation and knowledge. … He is gentle, he is honest, he is a good listener, and when he needs to give me correction, he is not afraid to ... or challenge me on a belief that I might have.

Elly valued her physician's compassion and knowledge:

> Finding a compassionate enough man in the field of psychiatry to sort of understand schizophrenia … and have the knowledge and the resources to sort of, play around with different medications until you find what suits you the best.

Art valued the truthfulness of his physician and mental health teams:

> … psychiatric nurse … and um, Dr Y., Dr X. … because despite how I was feeling, they always told me the truth.

Sam valued his physician and believed in providing his physician with feedback: "Don't judge the doctor, the doctor won't judge you. … If you don't feel better in a week or two, don't take it, ask for something else." Yvette compared her illness and her relationships around her illness to a marriage that requires work and trust:

> It is like a marriage, like life itself. You got to be on your toes … because he knows best. I guess he figures that a little visit with him you know, update things, and maybe for reassurance for himself.

Randy felt he and his physician were allies. He appreciated his physician noticing his efforts:

> He's one person that I have to say that has really changed my life around, and a little bit of effort from me, too, it is helpful. It is nice to have a pat on the back that you are doing a great job and that everything is working out and you, I am proud of you, and stuff like that. That keeps you going too and I am proud of myself for, for, learning a lot about my illness, and stuff like that.

Ingrid trusted her supports: "Listen to your doctors, get as much support, family support, sometimes people don't have support, that is the problem." Norm's professional team allowed him ventilation and support that got him "back on track", "Yeah, just to talk, and you know, get things on a positive track.

Olive valued her physician's knowledge about medications, "… thank God, he knows his chemicals…" Henry respected his physician and valued his ability to negotiate with his physician:

> I did tell him when I was getting a bit agitated, that I wanted a bit more medication. … I think I respect my doctor. If, when he asks certain questions, I respect that he has to ask those because he is the doctor. … He knows where he is coming from, what his training is and what is acceptable. But as the consumer or the mental health person, there are certain things that I have to say, and ask, too. And that should be respected also.

Symptoms continue despite insight. Therefore, the support of the physician is integral to creating and maintaining the stability necessary for fuller insight development. Physician and family build a team, but this team may also include a case manager.

9.2.2.2 Case Manager (CM)

While Ham valued his appointments with his psychiatrist, the regular contact and familiarity with his CM were his day-to-day support:

> G. (CM) and I … are very close together. … I mean, I don't have a doctor here 24 hours a day, and, you know, when he comes over, he just plays cards and bullshits.

Randy cited his mental health team as his main support:

> Basically, my two main support systems are … Dr X. and (CM). Those are my two. … I see CM on a regular basis too, and she's involved with Dr X., too and she does rounds with Dr .X. … if there is a problem …

Carl's mental health support person was critical to him and he advocated for others:

> … person should have a nurse who they can get in contact with at almost any time during the week. … A special nurse … you can call in case something happens. … Now, as long (you are) doing that, you will have no problem.

Olive valued her team for helping her sort out reality from hallucinations:

> My psychiatrist and my psychologist and my nurse have a lot to do with it. … They helped me to see things … I thought were hallucinations, and things like that. … They would tell me that it is your mental illness that is doing these things.

Olive also credited her stability to her mental health team and believed they reduced her hospitalizations:

> Absolutely, they are a part of my mental health team. … I believe that I need more than just a GP. … I believe that if you have the psychiatrist, a mental health nurse, a therapist, mental therapy and you are not going to utilize, constantly the emergency room and crisis line. …Ya, I would say it is important to have a health team.

Accountability was also appreciated by the participants. Henry valued the relationship, the practical support, and the accountability demanded by his CM:

> I had a CM for twelve years who … if I needed him there, he would come along and he was like a job coach. … He liked to play hardball, three strikes and you are out, so basically, I will be there for you, but with certain rules and one's medication, doctor appointments, stuff like that. … But he was really quite good.

Art also valued the accountability required by his CM: "because it keeps me from being complacent and when I become complacent, then I get ill psychologically. … Ya, accountability is very important."

The centrality and importance of professional support, particularly team-oriented professional support is undisputed and is of high importance. This will, therefore be discussed further in Chapter Twelve. However, in this section on establishing supports, the importance of peer support is discussed.

9.2.2.3 Peer Support

> OT: … it was a peer thing I facilitated. … I connected the two of them and she said later … how (it) instilled some hope for her. … There is a ton of power in that. … We need to feel some kind of commonality and it is therapeutic.

While family and professional support is vitally important to the recovery/insight process, in this study, peer support was deemed important by both professionals and

participants alike. Professionals spoke of the importance of the role in terms of social, emotional, and practical support:

> LSW: I am a big believer in peers too, and we have some really well peers here. … They are just wonderful supports … like, What should I do about my budgeting and what can I do about my cooking? … I think the support that the peers give to each other and the friendships that they build here makes a difference in people's lives; they are not so isolated and alone. … They know that their peers are living with it everyday … and to hear it from them is way more powerful.
>
> OT: I am getting a positive response … connecting peers to one another. … I've hand selected young people, that I hope, … they will be able to relate to one, … be able to share some experience and learn a bit along the way. And socially of course … I have had some nice successes in groups with clients exchanging phone numbers and seeing each other outside of groups.

Art's powerful commentary gives credence to the importance of peer support:

> I think what was lacking back then was support groups, peer support. … I was always being treated by professionals and when I started getting peer support *and* professional support at the same time, it sort of helped … the programs the clients got the most out of where they were run by peers.

Hannah pointed out that peer groups are a source of education for one another:

> I just found, like having peers, like in medical world, like in the schizophrenia culture, like people would be able to warn each other about certain side effects of medications …

Peer support offered reciprocity, safety, and understanding:

> Elly: Other people with similar symptoms, that have battled it that I've been able to help and have been able to help me in return.
>
> Irene: … is that I feel safe and no one will hurt me as long as I am here. Everybody knows me, and they all understand part of me because they have been through it all.
>
> Patty: … it's good to have friends around, like you can talk to them and tell them how you're feeling on this particular day, uh, and because they're going through the same thing. Basically … they can understand what's going on.

Elly also believed peer mentoring was missing from her early mental health support:

> Because if I had had a mentor, someone who came to my house … when I was down and in the dumps. … I had someone come and speak to me about their experience, I would, it probably would have kicked me in the butt to get in

> shape again, to just get back on my meds and go, and just battle my way through it each day.

Peers with the illness were a valued part of creating stability as their support mitigated the isolation, provided safety and a mutual understanding of the experience of the illness. However, other relationships also existed that more closely resembled friendship.

9.2.2.4 Friendship

Friendship is a human need. A psychiatrist bemoaned the under-utilization and capitalization of friendship as a powerful tool for insight development:

> Psychiatrist 2: I would love to do psycho-education to the friends of the 18 year old. And I think if you spend your money there, they have a better chance to get that individual to act as if he has insight. … Perhaps his girlfriend who now also has some form of psycho-education can actually support him on a certain level with insight.

Elly's friendships were a "saving grace", "So I call her for advice. … She's a saving grace for me to have." "True" friends and belonging were important to Ham:

> In 1988, I had no friends at all, and now, I have a lot of friends and friends are the most important thing in the world today. … True friends sure make a big difference.

Irene valued her friends:

> … friends … (one) who sees me quite often and she helps me, um, actually she can tell the way that I am feeling and what causes it, and that. And she is a good support, she supports me in lots of things. … That just comes with the friendship.

Friendships provide a sense of belonging. This belonging supports emotional stability. Stability is important for us all and most first person accounts of recovery from catastrophe recount the critical nature of personal support (Anthony, 1993) in the creation of stability. In this study, family provided a sense of belonging, love and support. Physicians were prized for their compassion, knowledge and understanding;

CMs for their role in accountability and regular support. Peers provided a sense of belonging, practical support, shared experiences and issues, role modelling, understanding, hope, and mentorship. Friends provided a sense of belonging, support, acceptance, constancy, and reciprocity.

Resilience is the capability of individuals and systems (families, groups and communities) to cope successfully in the face of significant adversity or risk. This capability develops and changes over time, is enhanced by protective factors within the individual/system and the environment, and contributes to the maintenance or enhancement of health (Mangham, McGrath, Reid, & Stewart, 2001, p. 3).

Early resilience research defined resilience using terms such as "invulnerable" and "invincible". However, these terms do not accurately describe the phenomena, because they imply an absolute resistance to damage, "… no one has absolute resistance; rather, it is more appropriate to consider susceptibility to stress as a graded phenomenon. Some individuals are more resistant than others but everyone has their limits" (Rutter, 1990, pp. 1-2). Resiliency theory uses risk factors and preventative factors to further explain resilience. Protective factors are variables that serve to ameliorate or decrease the negative influences of being at risk (Mangham et al., 2001). Resilience literature points to strong connections to competent and caring persons in the lives of people who demonstrate resilience (Wyman, Sandler, Wolchik, & Nelson, 2000).

Once stability is established by having these supports in place, the person has the firm ground to begin to learn more about their illness. These supports have the ability to

have an impact on the recovery process over the lifetime of the person with the illness and the importance of these supports and the influence of them on the recovery process will be elaborated on further in Chapter 12.

9.3 Learning about the Illness

The L in *C.L.A.R.I.T.Y.* stands for Learning about the illness. In this study, taking control in order to control the illness sparked keen interest in learning more about the illness. Anthony (1993) speaks about the stimulus to recovery such as books, films, and groups that may cause "serendipitous insights" (p. 6) about possible life options. Participants with the illness actively sought reading materials and sources of information on the illness. Ingrid enthusiastically provided evidence of this thirst for knowledge:

> I was at the library all the time. I read everything about neuroleptic drugs, and the side effects, about schizophrenia. I read books.

Others share how they sought more knowledge:

> Hannah: Oh, yes, mostly self-taught, from the Schizophrenia Society, I read up on their brochures … I've read books from the library.
>
> Olive: I've done some personal research and read some books like the DSM-IV and a, read a lot of stuff, so I am aware now of um any symptoms that might come up.
>
> Art: … when I was younger, ya, and also I took a mental health course at the college and learned all about the positive and negative symptoms.

Art's learning also meant applying what he had learned, "When I read an article with good information in it, I don't just slough it off; I try and look at it." Irene was grateful for her information about the illness that she received from her doctor:

> He's the one that taught me about mental illness and about schizophrenia … and he taught me things about myself, and about my life, and about what direction to go in.

The family member found that education provided for her in tandem with her mother's education was a "godsend" in developing a safety net for her mother:

> … this … called Strengthening Families, is, in a sense, a godsend … information. I got the support. I figured out that I wasn't the only person, the only family member who was out there dealing with this (and) … while she was in hospital, she took a course learning about her illness.

Patty got involved in her local Schizophrenia Society:

> I got involved with Schizophrenic Society … read all of their books, their videos, their, um, pamphlets, information. I have medical books, to read up …

Family education is critical for those caregiving a person with schizophrenia. Support groups for family members offer an avenue to "unburden", obtain some education, a sense of control, and gain relief from alienation around the experience (Reay-Young, 2001).

Professionals also saw value in education that might eventually assist in insight development:

> LSW: … they read the DSM-IV, or do lots of reading around their illness, and really, that helped them develop insight. … There are lots of different approaches and one of them will twig.

Family relationships are significantly and adversely affected by the onset of the illness and subsequent cycles during the *Period of Chaos*. Stability includes mitigating the damaging impact of the illness by educating the family toward a better understanding of the illness, providing grief and loss support for family, developing as a team and taking a team approach to the illness, and assisting family with new coaching skills to use with their family member with schizophrenia.

Educational support for families largely fell to the role of case managers in this study. The efficacy of providing psycho-education (not to be confused with cognitive

behavioural therapy) solely to patients is not effective while integrating families in psycho-education is deemed worthwhile (Lincoln, Lullman, & Rief, 2007; McWilliams, Hill, Mannion, Kinsella, & O'Callaghan, 2007).

Art's family blamed themselves until they received education on his illness:

> My dad blamed himself and took it out on me. … And after years of it, persistent, my dad started going to the agency I was with for schizophrenia and getting education about it and then he ended up being a good support.

"Information starved", the FM admitted her ignorance of the illness and blamed herself until she received some education:

> I didn't know what was going on with her. When I was a teenager, nobody told me anything. … Well, hello, I am the kid who is dealing with this. … I didn't know what she was taking, didn't know why she was taking it. I was just forcing her to take it, and I didn't know if that was normal or healthy or what, nothing, I had no support … certain people … approached me and said … There is this program out there, it is called Family to Family … would you be interested in it? And I was information starved at this time … So, I took this course, Family to Family … I learned a lot through this.

Long before Irene was ready to hear about the illness, her mother took an active interest in learning about the illness: "… but my mom learned a lot through books … and TV."

Several meta-analyses demonstrate the efficacy of family education that includes psycho-education components of communication, social skills training, and problemsolving (Lincoln, Wilhelm, & Nestoriuc, 2007). A new meta-analysis on psycho-education shows that there is a medium effect size for relapse and re-hospitalization reduction if both patient and family participate (Rummel-Kluge & Kissling, 2008). Family education eliminates the self-blame and provides tools for the family. Upon receiving education, the family is then equipped to provide more

emotional and clinical support to their loved one. Sarah spoke of her father, and Carol of her boyfriend:

> Sarah: … the end of your rope sort of thing, I will go sit with him and he will kind of fill me up … and kind of change me. … He kind of hushes and says don't worry about it.
>
> Carol: M. has always been my stronghold, always there for me. … He takes good care of me and my son. He is always there for me. It is too stressful for me to parent full time. M. has primary responsibility.

Zack acknowledged he could be difficult at times but appreciated his family's continued support in the face of his symptoms:

> They've been there when I needed people, I guess. … I can get a hold of them if I need to. … They know … I can be a handful and can be a pain in the ass.

Elly, Henry, and Norm appreciated their families' understanding and compassion:

> Elly: … my boyfriend, extremely … compassionate and understanding that I need to take this medication.
>
> Henry: … if you have a support system, you have to be thankful for that. It is not as important as the medication, but it is pretty important. … They understand that I have an illness.
>
> Norm: My, my family has been quite supportive. … I have a brother … he … came to me when I was first sick and kind of rescued me. … Norm, you need help … I chose to see a doctor, and the rest is history.

Irene's mother's mental health education assisted her in knowing how to provide support:

> Irene: My mom was a good support to me, she helped me a lot, she'd say things if I got sick or if I was getting sick, she'd say, Irene, you know, you got to look after yourself a little bit better. And I learned a lot from my mom, but my mom learned a lot through books and stuff like that, and TV, and that, eh?

Involving the family as part of a support team is useful for continuity of support:

> OT: … everybody on board, family meetings with parents and significant others and myself, writing things down and meeting regularly to review or to update or to change and to celebrate when there is successes, which is just as important.

The family member sought support from the mental health team when early warning signs arose:

> Dr X. and I know each other really well. …We had what looked like relapses starting … I phone … and give them the heads up, now.

Layering both family and participant learning about the illness seemed most effective in recovery. Learning provided knowledge and a greater understanding of the illness, and confirmation that what they were going through were manifestations of the illness. Additionally, they learned what they could anticipate and, perhaps, the aspects of illness over which they had some control.

During the *Period of Chaos*, people bristled and became angry when given feedback on their symptoms or behaviours, but as people became more educated about the illness, they are more open to accepting feedback.

9.4 Accepting Feedback

> Psychiatrist 2: … this person knows on a certain level that he needs other people to mirror to him how he is doing, he seeks out people who's opinions/mirrors he trusts. … We are social. We need to stand in relationship to and with other people.

The A in *C.L.A.R.I.T.Y.* is Accepting feedback. Accepting feedback from others is difficult in the early phase of the illness. A resistance to corrective information from others is a clear sign of a lack of insight (Beck, Baruch, Balter, Steer, & Warman, 2004). Initially, feedback is not appreciated and usually met with resistance. However, as people's insight develops, their resistance to accepting feedback diminishes. Accepting feedback holds two properties. Firstly, listening to feedback from others who perceive a problem, and secondly, once accepting this feedback, it is integrated.

9.4.1 Feedback from Others

People in this study spoke of initial resistance to feedback from others and a gradual acceptance of this feedback. Yvette admitted her previous resistance to feedback had changed, "I am getting so that now I have accepted it, I, it took me along time to, because I always figured they just wanted me drugged up but that wasn't so." Art was also resistant, but came to appreciate feedback from others. He saw this as growing in wisdom:

> They were my eyes and ears and they would say, Art, you seem kind of off today, or they would give me positive feedback. … Before I used to get angry, but not no more, I think studying the proverbs helped me with that, it says, that a wise person accepts correction and feedback and a fool doesn't, so I think I took that kind of seriously.

Hannah, Olive, and Irene conceded that their openness to feedback was dependent on medication adherence:

> Hannah: … and that is one thing I told the nurses over at, at the college, I told them, I won't appreciate it right away, but when I am back on medication, I will appreciate your honesty and letting me know that things are not right and it sort of makes me realize I am not fooling anybody but myself.
>
> Olive: When in the past … they would notice things. … And I would brush them off … you know, so that I didn't notice the symptoms or anything and that's when M. and them guys and oh, my room-mates and that would notice (laughs). They would notice things that go on. … So after a while, I started to think about it … when I was on medication, I would start thinking about some things, and I was able to figure out what was realistic and what was not, on some aspects, but not on all.
>
> Irene: … sort of try and get somebody else to check me, my sister and my mom, both are pretty good at helping me sort through what is real and what is not … discern what is real with, and what is not real. … I accept it, now, where as before, it used to irritate me … really upset me if somebody would say, you should take a shower or bath.

Henry accepted feedback, but sometimes found it difficult to take: "Sometimes, I can take criticism, but sometimes it is pretty hard." He found it easier to accept feedback from a mental health worker than family.

Feedback for Norm served to strengthen his resolve to manage his illness better:

> … some of the feedback I get is, uh, quite … and it sort of makes me want to toughen my resolve and stand up for myself a bit more. … Could be negative feedback, yeah, yeah, it uh, it's good for me, you know (laughs).

As the *Dynamic Period* progresses, there is less and less resistance to the feedback from family and friends regarding symptoms of the illness. Rather than being resistant, people with the illness now make changes as a result of the feedback from others.

9.4.2 Integrating the Feedback

The family member provided her mother with feedback. Others noticed their own willingness to listen and make the necessary changes:

> FM: … she kind of catches on where I am going with this, Mom, you phoned me three times today on the same conversation, is everything ok? Oh, I have haven't I? Oh, maybe I should to a doctor or get my levels checked?
>
> Art: They can tell when I am off, (we) talk about it, maybe take a couple of days off and rest or work less hours that day, do something at work that is not so stressful, like paper work or something.
>
> Irene: … like Henry will let me know and I don't argue, I know he is right, when he says, Irene, you should look after your hygiene a little bit more, I don't really get defensive. Ya, I do, if he says it.
>
> Yvette: I would say, listen well to what your friends have to tell you, if they feel you are still being … most of all listen to your friends, your family. … They can give you a lot of information if you are going to receive it; being willing and open mind to receive help that is there before you get into a situation where you are in the hospital.

Where there is less resistance to feedback, people begin to incorporate the feedback as positive and make the necessary changes. However, this level of insight is at least in

part, hinged on a critical pharmaceutical development — finding the right medication.

9.5 Right Medication

Finding the "right" medication was a very strong finding within this study. Sixteen of the nineteen participants reported how important the right medication was to their insight development and wellness. Finding the right medication required time, medication trials, and augmentation strategies. Olive felt like a guinea pig, as her physician adjusted her medication to find the right combination:

> … so, he was able to put me on the right medication, finally, like an experiment. I was like a guinea pig, there for a while, but that is what happens. Every human being is different, right, and we all need different meds, right?

Yvette's physician also adjusted her medicaton, "It did take numerous different kinds of, ah, medication, but none of them done as well, I never did as well as what I do on this, what they have me on." Elly described some of her medication trials and how finding the right combination of medications made the difference for her:

> … it's been a series of years and different medications, and switching them up and taking them at different times, and taking different ones, um, to find the right combination for me. The kicker has been finding the right medication.

Henry recommended finding a physician willing to adjust the medication if it is not right, "I think you have to find medication that works, and if you have a problem and don't seek help, and the first medication doesn't work, don't give up, try another one." Art described how he had dragged his heels about going onto Clozaril, but once he was started on this controversial medication, he felt immediate relief. He shared how this medication change came about and the benefits he experienced:

> Clozaril is a miracle drug. … when I was on Risperdal or Seroquel, I couldn't get well.

Other stories reflected this "miracle":

> Irene: When he finally got on risperidone … he was like a different person altogether. He was just the opposite of the way he is now. … He's so good and so smart and things are going his way.
>
> Carol: The medication I am on now, works.
>
> Ham: … clozapine … this is the best. … This the best stuff that I have ever taken in my whole life.

Interestingly, even the "right" medication did not necessarily provide full symptom relief but improved the ability to discern reality from the psychosis:

> Norm: The Risperdal is better … the delusional beliefs are still there, … but it better lets me discern reality from, um, delusional beliefs or thinking.
>
> Randy: The Clozaril has helped me so much; it straightened out my mind, made me have normal thoughts.
>
> Sarah: … because the Clozaril was supposed to be better … it just works better. … It just brings everything into a perspective.

Hannah's side effects were reduced on her "right medication" and this made medication adherence easier:

> … because before I got on the risperidone, ah, the side effects were really horrendous. … I can't stress how really important it was for me to, ah, find the risperidone and be able to have a stable life on medication. … The Risperdal, like it is a gentler, more specific medication, and I have been able to stay on it and not want to get off of it.

The family member reported a right and better medication:

> Clozaril is wonderful … and they took her off the Haldol and put her on Risperdal. She is also on Risperdal and life is pretty simple, pretty easy.

Professionals also acknowledged that right medications make a difference:

> RN: … but first and foremost, you got to find the right medication. … Sometimes, there has to be to find that magic dose, not magic dose, but the most effective dose and the most effective combination of doses.

Finding the right medication was viewed as "miraculous" as it diminished symptoms, reduced side effects and provided a new ability to reality test. Finding the "right

medication" produced a more stable life, improved relationships with people, gave people more hope and an improved quality of life.

9.6 Conclusion

The *Dynamic Period* is the middle and very active stage of the process of insight development. Here, people take affirmative action and responsibility for their illness as they develope *C.L.A.R.I.T.Y.* by taking **C**ontrol and **C**reating stability, and finding support people. They **L**earn about the illness and begin to develop the ability to **A**ccept feedback from others. Additionally, they are finally placed on the **R**ight medication. Finding the right medication allows the person to evolve into a fuller insight development. There appears to be a sense of relief, some pride and ownership that comes with a sense of greater control and empowerment at this stage of recovery. The *Dynamic Period* is continued in the next chapter, which describes Developing **I**nsight**, T**reatment Importance and **Y**ielding to the Illness.

CHAPTER TEN THE DYNAMIC PERIOD CONTINUED

> FM: I swear, Alice in Wonderland is a wonderful way of looking at someone who is suffering from psychosis world. … It is like she can see Wonderland, but she is on this side of the looking glass and she knows she is on this side, but it is there and she can hear and she will think people are talking about her and you can tell that she is ignoring it. … She is aware that it is inappropriate to respond to it.

10.1 Introduction

This chapter continues the *Dynamic Period* and completes the *C.L.A.R.I.T.Y.* pathway. The **I** in *C.L.A.R.I.T.Y.* stands for **I**nsight and there are *Four Types of Insight*. The **T** stands for the recognition of the importance of **T**reatment. Finally, the **Y** stands for a **Y**ielding or acceptance of the illness that contains two unique aspects of this yielding to the illness.

Very little research has been documented identifying or typing insight constructs. Rickelman (2004) speaks of "retrospective insight", whether a patient believes he or she is sick now or has been sick in the past. Lewis (2004) reports "usable insight" can reduce suicide risk, assess what has been lost and realistically appraise the future. Tamminga (2003) views antipsychotic medication as "mechanistic insight", and the phrase indicates the leverage that antipsychotic medication has over a lack of insight. Roseman et al. (2008) found individuals with "intact insight" were better able to manage their symptoms, which results in a better quality of life. Eack and Keshevan (2008) describe a form of insight in schizophrenia called "foresight": the ability to think of the long-term consequences of one's behaviour and use this information to guide present and future actions. More specifically, they measured two items in their study: "Inability to assess long-term consequences (good and bad) of behaviour;

difficulty of forming long-term plans" and whether people with schizophrenia, "Could see the future outcome of behaviour; took a long view" (p. 257). People in this study demonstrated they had the foresight to assess the long-term consequences of their behaviours and consequently took action that avoided negative outcomes and produced positive outcomes:

> Art: If I don't take care of myself, that is me (becoming psychotic again).
>
> Ham: I never get behind on nothing. I am always on top of them. I have to be on top of them because … (if) I don't take these pills, the world will go crazy … these medications keep me level and that is ok.
>
> Irene: I found that if you budget your money properly, and you stick on that budget, you don't get depressed, um, if you have your hygiene better, you don't get so down because you are clean looking and you feel good about yourself showering every day, and stuff like that. If you let yourself go and you spend all your money and you are broke a week or so before payday, ya, you will get depressed.
>
> Zack: It is a big thing, otherwise I get into trouble. I have to keep myself occupied or I get into trouble.

This study appears to support the concept of foresight as a type of insight. However, four additional types of insight were gleaned from the data of this study. Three are unique to this study and one is a further dimension of Rickelman's (2004) retrospective insight.

10.2 Four Types of Insight

> Psychiatrist 2: So firstly, it is something mysterious and something you can't see, so all we see is how people act and what they say, and through those things we deduct if they have insight or not.

Insight is developed throughout the entire insight development process. However, specific types of insight are developed and deserving of discussion. Seeds of insight were planted by the *Trinity of Crisis* and fertilized by support, education, feedback, and the right medication. Insight grew and bloomed slowly as people in this study

adjusted to their new "right" medication and began to sift and discern symptoms from reality. This supports Tamminga's (2003) report of "mechanistic insight".

Four Types of Insight were derived from the data: *introspective insight, interpersonal insight, retrospective insight,* and *strategic insight*. Firstly, *introspective insight* is the awareness of self and of the early warning signs and biofeedback (messages from the physical body) that something is threatening one's wellness. This self-awareness precipitates the second characteristic, *interpersonal insight*, the ability to know when and where to seek help. Thirdly, experience and maturity yield *retrospective insight*. However, insight is much more than noticing and seeking help. People with good insight have tools and strategies to apply when symptoms become intense. These people have developed *strategic insight.* This section more thoroughly describes these aspects of insight.

10.2.1 Introspective Insight

> Introspective is defined as: having the quality to look within, examining into one's own thoughts, feelings and mental conditions, close examination or inspection of something. (*Oxford English Dictionary*, 1985, p. 1474)

Introspective insight is having this ability to examine how one is thinking and feeling and behaving and then to determine, in this case, if there is anything of concern that threatens wellness. "So in other words, losing insight, might actually be a sign of early relapse, because we can't measure insight, all we can measure is the behaviours that goes with it" (Psychiatrist 2). The participants with insight were able to introspect, notice and monitor what they were thinking, feeling, and doing:

> Ingrid: I don't know if it was Plato … but somebody said, Know thyself, and I have tried to get to know myself. … I've got to the point that I know myself

> so, well, by my bodily symptoms. … I have tried to analyze it, tried to figure out what is really happening here, that I am having these symptoms.
>
> Yvette: I spend a lot of time, ah, paying attention to how I behave, how I act when I am doing it on a proper basis or normal basis.
>
> Randy: I know more about myself and my illness, and stuff like that.
>
> Hannah: I know what I am like normally, and I can sort of realize when I am going off the rails. I notice changes in my body and mind and spirit.
>
> Patty: You get in tune with your body. If you've been in this body as long as I've been (laughs) and, you know, you ask questions yourself.
>
> Olive: I am aware of how my body is functioning and how my mind is, and what I see when I am not well.
>
> Irene: I get … warm. … I can tell that when my meds are starting to taper off. I get a little flushed.

These comments regarding changes in bodily symptoms highlight the biofeedback from bodily symptoms and cognitive changes. This self-awareness made study participants acutely aware of the indicators or early warning signs of relapse. Talley (1998) reports that self-regulation skills used by people with schizophrenia include the ability to recognize their early warning symptoms, reduce stress, and seek help. Many of the study participants noticed negative symptoms as their early warning signs. Negative symptoms of schizophrenia are common, enduring and a debilitating component of the psychopathology of schizophrenia (Stahl & Buckley, 2007).

Negative symptoms can include flattened affect, alogia, and avolition (American Psychological Association, 2000). Irene noticed she began to neglect her hygiene and to isolate: "My hygiene is poor. I want to be by myself more as time goes by." Carl's hygiene declined as did his sleeping and eating:

> … when you are not getting enough sleep, (coughs) not sleeping properly. That is a big problem, eh, if you don't sleep properly. You start getting dirty and lazy. You then, stop, stop eating properly.

Patty slept too much, "I know when I'm getting ill … if I find myself sleeping too much." Henry isolated and noticed an unwillingness to take his medication, "Uh, isolation, don't want to take my medication." He also noticed a vague feeling of unwellness, "I don't feel quite normal." Sam reported agitation and depression as his early warning symptoms, "Oh, my legs start to … I tap my legs. … The second one would be depression. … Uh, negativity, a little bit negative. Um, unsure about myself at the time I am feeling sick."

Carol noticed her early warning signs when her anxiety and stress levels escalated:

> I know that I am getting sick because I get so anxious, go, go, go, keep moving, can't sit still, need something to do. … I get stressed.

It seemed difficult for her to determine if it was because she was beginning to get sick that she was less able to manage stress or if the stressors were making her sick. Irene admitted she had often ignored the negative symptoms or the stress until she was too sick and lost insight:

> Well, it depends on how far, how deep I go, if I go for help. Usually, when I am that far gone, I don't want my medication.

Other participants seemed more troubled by the positive symptoms which were their first warning signs:

> Irene: Oh, ya, well, *at first*, I hear whispers. I know it is my illness, I know nobody talks to me, and when, nobody else hears it but me.
>
> Norm: I occasionally can see or tell when I am getting sick especially when it is in the *initial* (stage), I have, what do you call, forces acting on me, and they become stronger, more prominent, and I have uh, uh, less freedom you might say. … I know that they're not real, because I can't really see them.

Randy's positive symptoms never went away, but he noted his early warning signs were the intensification of these positive symptoms as: "*slowly* came on the loudness of the voices, the hallucinations and the paranoia." The family member was able to see examples of introspective insight in her mother:

> Those are like the *early warning signs.* … She feels that if you are wearing a colour and she is wearing the same colour, that you can read her mind, little, she will kind of gingerly say that. … She will hold it in around people. …

Regular introspection helped the participants to keep close tabs on how they were thinking, feeling, and behaving. This introspective stance is where the person with the illness becomes increasingly aware of their own body and mind, and accordingly, make adjustments. This biofeedback moves the external locus of control to an internal locus of control and allowed them to identify early warning signs that threatened relapse.

> OT: It is knowing and understanding it, and then recognizing when things change … and they know when symptoms come up, and they know how to deal with them.

Once aware, the people in this study were able to utilize interpersonal relationships to reality test and to seek help from others.

10.2.2 Interpersonal Insight

Interpersonal insight means knowing and recognizing early warning signs that facilitate understanding that they may be in danger of relapsing and that help is necessary. They begin to seek feedback from others as a way of managing the illness.

Hannah and Norm shared how they sought feedback from others for reality testing:

> Hannah: Yes, family and good close friends, ah, I go down to the …Canadian Mental Health Association Clubhouse, and if … I saw on the news or

> something I can check it is real with them. … Yes, I have to get other people to check out things that seem a bit odd.
>
> Norm: What I try to do is make it more real by taking what is imaginary and going out and facing the people. … I know in my head if I face up to a situation that I'll get through it, and that it becomes more in perspective later on.

Sarah sought feedback when her symptoms were going off like "whistles and bells":

> I phone people usually and say look, you know, my symptoms are going off like whistles and bells right now, and can you help me? … They say, Shh, no, no, no that is not what is happening you know, this is what is happening. And then it is ok.

In fact, a candid opportunity was captured during the interview when Sarah became paranoid. This piece of transcript describes her ability to seek feedback from others when she becomes paranoid:

> Researcher: Are you ok?
> Sarah: No, I feel like I am being trapped or something
>
> Researcher: Do you? Do you remember why I am doing the study?
> Sarah: Ya.
>
> Researcher: Ok, so my research is to help people with schizophrenia.
> Sarah: Ya, ok, I feel like I did something illegal or something. Did I?
>
> Researcher: No, I am interviewing you because I think that you have some information that can help me, help people with schizophrenia.
> Sarah: Oh, ok.
>
> Researcher: So what can I do right now? How can I help ease that feeling of entrapment?
> Sarah: Stop listening, not listening.
>
> Researcher: Not listening?
> Sarah: To that entrapment.
>
> Researcher: What is it saying?
> Sarah: It is saying that I did something very bad and this is.
>
> Researcher: So you use some sort of thought stopping techniques?
> Sarah: Ya.
>
> Researcher: So that is helpful for me to know that that is one the techniques that you use to break?

> Sarah: No, if something is wrong or something like that, I will ask, you know, did I do anything wrong?
>
> Researcher: So getting that feedback from me is helpful?
> Sarah: Ya.
>
> Researcher: When I say no, you haven't done anything wrong.
> Sarah: Ya, ya.
>
> Researcher: That is a very good strategy, Sarah.
> Sarah: Well, I have found if you don't ask sometime, (you never know).

Mental health professionals saw responding to this need for feedback from others and reality testing as part of their role:

> LSW: … like when somebody with schizophrenia is saying this is happening to me … the worker is able to say … that is part of the illness or that is normal, so that they can kind of like separate it out as to what is everyday normal living, as to what is part of the actual illness.
>
> OT: … I guess part of my job is trying to get people to doubt the psychosis and trust what we would see as reality.

People actively sought feedback from others as a method of reality testing and symptom management. Norm eloquently pointed out this prompting of help from others is "help seeking" but not necessarily seeking professional help:

> … the best thing I can say about insight is that. … It's the practical things that you do. Um, when uh, it's like, when you *first* feel yourself getting sick, you say, um, how can I best describe this? You first feel yourself getting sick, then is the time to act. … It would be manageable. But when you first notice yourself on a downward spiral, is to get help then, and it doesn't have to be, you know, you call your psychiatrist in the middle of the night; it could be something simple like call a friend … just reach out.

Art agreed, "… sometimes just a simple matter, calling a friend." Hannah actively sought support to confirm or deny her beliefs and used her informal supports first:

> Yes, family and good close friends, ah, I … can check if it is real with the people at the Clubhouse.

Elly understood the need to reach out, "Never be afraid to ask for help, never be afraid to reach out". Randy, Irene, Yvette, Elly, and Olive were all aware of when they needed professional help:

> Randy: I am paranoid practically every day. … Sometimes when they are really really loud … that is basically when I would probably go to the hospital. … I had to get some help; I had to tell my doctor.
>
> Irene: When I start hearing whispers … I am not the same and that I get depressed … I will go for help.
>
> Olive: When I feel that way, I contact T. to make an emergency appointment with Dr X., so I can come in and get diagnosed by him, so he can either do a medication change, or give me a shot, or put me in (hospital) for a couple of weeks, or anything. I contact T. right away.

The OT agreed that a higher level of insight was the awareness something was wrong as well as the ability to seek help:

> … most of them have symptoms, but they have learned that they are symptoms …and they know what to do with them. And if they get to be a certain level of difficulty, then they tell somebody, they talk to their doctor.

Peter reported that insight included being self-aware that "the frequency and duration and volume (of symptoms) has increased over time", but also knowing when and where to seek help. While Lappin et al. (2007) demonstrate that not all help-seeking clients conclude there is something wrong or that their difficulties reflect the presence of a mental illness, participants in this study seemed aware enough to acknowledge there was something wrong. However, they also utilized self-help strategies as much as possible before seeking professional help. They knew when their illness was exacerbated and relied on their maturity and experience in a retrospective manner.

10.2.3 Retrospective Insight

As mentioned earlier, Rickelman (2004) reports *retrospective insight* as present when a patient believes he or she is sick now or has been sick in the past. However,

retrospective insight appears to contain further dimensions. Firstly, there is a looking back, a remembering, a stocktaking that adds to current insight, and secondly, there is the development of confidence and maturity, honed through experience and learning that contributes to their insight. Bill McPhee (2007), a man with schizophrenia and publisher of the Schizophrenia Digest, defines confidence as the "ability to project on the outside how we feel about ourselves in the inside" (p. 56). This is developed by looking back and in retrospect, gaining confidence and growing maturity in living with the illness. Reno (2004) reports that older relatives of younger people with schizophrenia show greater personality adaptability and moderation of beliefs. Moderation and personality adaptation are factors in the maturation process. Roseman et al. (2008) find individuals with "intact insight" may be better able to manage their symptoms which results in a better quality of live. Their study was comprised of middle-aged and older people with schizophrenia or schizoaffective disorder. The mean age of people in this present study on insight was 46.8 years of age. It is possible there may be some correlation between insight and age.

Art noticed that his belief that something bad was going to happen did not eventuate. He used an inventory to take stock of how his day went:

> I know that nothing has happened over a period of time, and then I realize it wasn't real. … So I do an inventory. Did I take my meds? Did I get rest? Did I have fun? Um, oh, the other thing that helps is listening to gospel music. … I get comfort from that.

Irene described how stocktaking or an inventory of the day helped her set new goals:

> … going over your feelings and what is going on in your life … I kind of, just do, like, a session or inventory or … like setting goals and stuff like that. Plus I also go over the days I wasn't feeling good and know where I went wrong, and go ahead and change, maybe, a bit of my life to make it better.

Ham looked back as well to tell how he is doing, "… when I look back, now to then, I can tell." Art remembered and the feelings were stirred up for him:

> It is like a feeling, an awful feeling. … Then, oh, ya, I remember that, but I have to take that as a positive now. Oh, ya, if I don't keep doing what I am doing I could end up back there.

Norm's reflections of the past assisted him in not making the same mistakes:

> I tend to reflect a lot. …The way I behave now, I learned from the past that I try not to make the same mistakes I made in the past. … Maturity has taught me to not to waste time and energy … and now, looking back and see where I went wrong.

Cognitive dissonance is another reminder of how far they have come. Dissonance theory states that inconsistent cognition creates psychological discomfort, which motivates people to alter their cognition to restore consistency (Festinger, 1957). "Seeing themselves as they might be" creates cognitive dissonance and reinforces people to change their beliefs, attitudes, and behaviours in order to restore harmony or consistency (Leippe & Eisenstadt, 1994). Hannah spoke of seeing a street person with untreated schizophrenia, "I figure, that there, by the grace of God, go I." For Art, seeing another person with acute schizophrenia was also a reminder he must take care of his illness, "Ya, oh ya, sometimes I go, if I don't take care of myself, that is me." Henry remembered seeing one person who he knew was off his medication and he knew it was not good:

> One guy went off his meds and got sick. When I seen that, I never seen that before, but I could recognize that he wasn't on his medication, and that is, like … so it wasn't good.

Sam had developed confidence and trust that he would know what to do when he began to get sick, "So, it's easy … it's not, after a while it's easier, if you be true to yourself as much as you can. It just comes automatically." Randy described how he had built confidence through his past accomplishments:

> … doing things on your own and succeeding at them. … I took these workshops … and I completed them all. … That gave me a little bit of confidence.

Maturity and experience play a part in being able to remember the past and see goodness in the future. Torrey (2005) remarks, "Increasing age has a way of making us appreciate, although retrospectively, whatever physical and mental capacities we had in our younger years" (p. 14). In addition, recent resilience research indicates that resilience may be more "ordinary" than previously thought and actually be a phenomenon arising from "ordinary adaptive processes" (Masten, 2001, p. 234). These adaptations may take place over time.

Through experience, Ingrid was now aware that her dreams could provoke her psychosis, and she had learned to not give them so much weight: "How all my illness initially started was from dreams. I'd have a dream and I thought there was a real big meaning in the dream. Now I don't take it so seriously." Patty and Susan laughed as they reflected on their experience of managing their illness:

> Patty: I've had a lot of practice.
>
> Susan: We're growing up!

Peter recognized how his experience had provided him with tools to manage his illness:

> … over time, but I have learned different coping mechanisms where I can. Before, when I first acquired the illness, I had no coping mechanisms, but now … I can cope with it, I can deal with things.

Olive stated that her judgement could be trusted now, "and a belief in yourself, you know, I didn't used to trust myself, but I trust myself impeccably now, I really trust myself." Carol also noticed that as she aged, she was getting better at managing her illness:

> I am old enough to understand that I have to take medication. … I am probably getting better at managing my illness.

Irene's maturity and remembering allowed her to see that life is good:

> … as I am getting older and I am starting to really value my time with my family, I am starting to value the joy I have in the heart, value my friends and value myself, feel good about myself. Like I think when I was first diagnosed, I didn't think anything was good.

Randy recognized a growing competence in managing his illness:

> … my mind is getting stronger, or I am learning as we go … and um, I feel like I am more mature, I understand my illness a lot better than I did before. … I have got just a little bit smarter, or ah, a little more keen about my illness.

The LSW also saw that age and maturity may assist insight:

> … well, I think the longer they have it … they are able to know that that is what they have, that they have some more insight into their illness. … It is the experience. People just get better at coping with it over time.

Maturity and experience appear to play a role in insight development. Learning over time, through trial and error, through gains and losses, people identify what works and what does not work. Time mitigates rebelliousness and fosters acceptance and strengths. In addition, this continual reminder of the pain and dangerousness associated with relapse assists in the reconstruction of dangerousness, as discussed in Chapter Eight. Studies demonstrate that between 20% and 65% of people achieve "good outcome" over time, ranging from mild impairment to functional recovery (Carpenter & Kirkpatrick, 1988; Davidson, Schmutte, Dinzeo, & Andres-Hyman, 2008; Jobe & Harrow, 2005). Haro et al.'s (2006) study indicates a deteriorating course of the illness, over the long term, but that relapses are fewer and less severe. However, their study findings also indicate that the longitudinal course of the illness provides the opportunity for maturity and experience to play a role in remission, and despite their symptoms, people have greater management skills to deal with those

symptoms. Very little research exists on the role that maturity and experience of middle age plays in the recovery process.

10.2.4 Strategic Insight

> Psychiatrist 2: If all we want is for someone to acknowledge that they need some form of treatment and recognize who will offer it to them, I think we have a larger portion of people that have insight. But if we want people who try and live with their chronic illness … then I think the proportion really shrinks.
>
> Recovery from a mental illness clearly entails the development of coping skills and the ability to recognize when to access various resources to sustain one's mental health, whether those are formal services, alternative treatments, friends or solitary time spend engaged in creative activities. (Onken et al., 2007, p. 14)

Strategic insight is the ability to know that symptoms are interfering with functioning and to be able to provide the self with effective, positive strategies to deal with the interference. Higher levels of hope reduce passive coping strategies and foster more active ways of coping (Lopes, 2008). Strategies of active coping fall into three distinct categories: self-talk/pushing self, maintaining stability, and controlling the variables ("controlling the variables" is an in-vivo term (exact words) coined by Henry to describe personal responsibility).

10.2.4.1 Self-talk/Pushing Self

> Patty: I talked to my mom on the phone, and she said, Just be like the frog in the milk, hon. And I said, What you are talking about mom? And she said, Just keep paddling till you make butter and hop out.

Self-talk is a cognitive strategy used by several of the participants:

> Sam: I overcome that with mental thought. I just keep myself mentally happy by just thinking that, well, I've done the best I can.

> Norm: I do use self-talk … discerning reality from what is in my imagination. I find that I desensitize myself to the type of gossip that you hear.
>
> Yvette: I make myself do it, I tell myself, this has gone far enough, this is ridiculous. You get out and go do what you are supposed to be doing. … I really have to work hard at it … self-talk to myself a lot. I know a lot about myself … just myself, becoming aware of it, aware of yourself, taking the time to learn about yourself.

The OT remarked on a woman with the illness who "pushed herself" out of her comfort zone:

> I was overhearing these two young females talk, the one with schizophrenia, … was invited to go after the game up to the pub in the hockey rink. … And she has been asked to do that before, and she has always declined. And so, she had made up her mind that she was going to say, yes, next time she was asked. And she had thought ahead of time what she was going to talk about, and how it might go. And so she was asked to go up, and she went, and it was, she was quite pleased. … She said, That is the first time that I felt like I haven't been ill.

Sarah "pushed herself" to take control of her illness:

> I don't let schizophrenia hold me back. … I do whatever I want (laughs), you know, I am not going to let an illness boss me around.

Ingrid and Olive read self-help books that provide guidance for self-talk:

> Ingrid: Self-talk. … I have always … self-help authors … but it helps me. … I will act now.
>
> Olive: … self-help books, ya, um, the wisdoms of other people are incredible, and it can really make a change. … Some people's theories and philosophies are just exactly what you need, to fine tune or teach yourself.

Patty used self-talk to discern reality from delusion:

> And I still had to say to myself, well, maybe that's you know, maybe it's just my mind playing little tricks on me, or, you know.

Art reminded himself over and over that his delusional thoughts were not real, "it is not real, it is not real, it is not real." Sarah's delusions involved a woman named Mary. She used self-talk to "get rid" of Mary from her mind, "I just say, Mary, I have

had enough of you for today, will you please go away? … Ya, it makes her disappear sometimes."

Olive lived near an airport and her paranoia involved planes flying overhead. She explained how self-talk kept her paranoia and fear down:

> I still get paranoid about planes flying over. … I don't convince myself it is not spying on me, I just give myself that idea that maybe they are not. I try to come up with another thought, besides, Oh, my God, it's flying overhead.

Patty used self-talk so she could go about her normal day-to-day business:

> I still get overwhelmed, but I find myself, I talk to myself. … Come on Patty, you have to do this, like going into the bank.

Elly used self-talk as a way to defeat suicidal thoughts:

> … you really have to check in with yourself and learn how to go, Ok, I'm feeling this way, I'm having these thoughts, but I'm not going to take action.

The family member also noticed how her mother used self-talk to cope:

> … when she is having them … she will talk herself out of it or through it. … She will catch herself and she will say, Oh, no, that is a silly thought. So very early on … I will catch her talking herself through this.

Strategic insight includes the aspects of self-talk and pushing self. Self-talk is necessary to overcome, manage, and keep in their place the residual symptoms of the illness in order to maintain healthy function. Pushing self is a tool to avoid being overtaken by the illness. Strategic insight also includes the important aspect of finding a balance in order to maintain some stability over their illness.

10.2.4.2 Maintaining Stability

Roe and Chopra (2003) note a coping paradox exists whereby for some people coping consists of engaging in activity, while for others, coping consists of slowing down activities, "both decisions guided by a core, active self" (p. 342). Achieving stability

is a long, hard road. Participants in the study were reluctant to do anything that might threaten their stability, and a conundrum existed between achieving and doing so much that their functioning deteriorated. They managed this conundrum through the strategy of balancing the activities that affected their functioning. Maintaining stability is the strategy used to achieve the fine balance between healthy activity and stress management. Elly qualified that stopping for a rest was not quitting; she supported "pushing yourself" but resting as well, "I can't stop, I can't give up. … There is a difference between not giving up and not stopping." Sarah worked at balancing herself by not pushing so hard and relaxing, "I try … to relax as much as possible. Don't push myself."

Norm recognized he was not superman:

> I try not to push anymore. Um, probably the, the most important thing that I learned is that, uh, you know, I'm human like anybody else. I'm not superman; you know I can't crash through walls and stuff like that. … So just to try to be as realistic as possible.

These participants were careful to maintain their equilibrium:

> Hannah: … there are some days, I just cannot get out the door. That's when I realize, Ok, I better take a day off. Like, I am having real difficulty coping today.
>
> Sam: Physically, I feel stable. I don't feel like I am out, and ready to go out into the world, and get a job, and have kids, and go to school, and raise a family. I don't feel like I'm ready for that yet. … I'm very, very careful about my emotions. They can be overwhelming.
>
> Art: … to look at my illness seriously, that is why I am only working part time … my … dream job, it is all up to me. I can work one hour or I can work twenty.
>
> Sarah: The only thing that stops me back from working full time and stuff like that is because I get too stressed out. I get really tired and weepy and it is just too much for me to handle.

Equilibrium is important. This equilibrium seems to reflect what Fowler, Garety, and Kuipers (1998) label "strategic withdrawal" (p. 6), a removal of self from triggering

episodes or activities on “bad days”. Some of the participants indicated that working or working full time could upset that equilibrium and might trigger activities that would overload their ability to cope. Art shared his strategies for pacing and balance:

> I use a little slogan called M.A.L.T. M for medication, A for anger and feelings, when they come up, talk about it, L for loneliness, so I am not isolating and have a support group, and … when I am tired, I rest.

Irene stopped her poetry writing and Art censored his television viewing because they recognized that these activities could provoke symptoms:

> Art: I am very particular what I watch on TV and what I have on the internet. I don’t watch pornography, and anything too violent. … I find it helps me with my illness.
>
> Irene: I think I know why I got sick when I was writing poetry. … I get emotions in there and … it is too much for my mind to grasp. … I am scared to write now … I don’t want to take a chance of getting sick.

Ensuring some quiet time helped both Carol and Irene cope:

> Carol: I get up half an hour before everyone else is up; I have coffee, a smoke, take my pills, get washed up and have more coffee. … I get some space that way, not a lot, just enough.
>
> Irene: I like being by myself. I can invite myself out.

Henry provided sage advice to his peers on how to maintain balance: "If you gotta take something on, you gotta let something go. It’s really a fine balance.” Norm issued a warning to his peers reminding them of the consequences of not maintaining this “fine balance”: “You could really fall a long way.” The prevailing message in this section is to be careful to ensure the fine balance between healthy functioning and being overwhelmed. This fine balance is maintained by minimizing stress and maximizing strategies that ensure personal responsibility in all activities of daily living. Strategic insight is about self-talk/pushing self and maintaining stability, but also includes “controlling the variables”. Controlling the variables includes taking

personal responsibility and employing coping strategies around self-care/activities of daily living and coping strategies.

> Henry: … if you don't control the variables, then they get out of hand. … Well, it means I can't go and play pool every day. … Room management, taking care of yourself, and doctor appointments.

As noted earlier, "controlling the variables" is an in-vivo term coined by Henry. Controlling the variables is comprised of two characteristics: personal responsibility to manage daily living and coping strategies to manage the symptoms of the illness.

Personal responsibility also involves taking responsibility for the illness and eschewing placing any blame upon others. The family member was well aware from watching her mother's insight development process, of the importance of personal responsibility in managing routine activities, such as self-care:

> … it is a life management change, it's all those things, because when you have diabetes, your medication is not your cure, it is your control, but you also have to manage your diet.

The OT acknowledged the importance of structure and routine in the lives of people with schizophrenia:

> … well, I think that people with schizophrenia typically really do thrive or do best with structure and predictability, and um, consistency.

Ham and Irene took personal responsibility for their finances:

> Ham: I am totally legal in everything I do. My bills are paid up … I never get behind on nothing … I am always on top of them. I have to be on top of them.

> Irene: I found that if you budget your money properly … you don't get depressed. … If you let yourself go and you spend all your money, and you are broke a week or so before payday, … you will get depressed.

Others described how they controlled the variables of self-care:

> Hannah: I practice good sleep hygiene habits. I keep to a fairly consistent weekly regime … eating properly … going for fibre. … I make sure that I get

> enough lettuce and vegetables. And it has helped me lose some weight, some extra bloat from the medications.
>
> Norm: One thing that helps me cope is just … try to keep good habits helps me cope. … All habits, eating, sleeping, uh, you know not drinking, not staying up late, good sleeping habits, good hygiene. Just general healthy living helps … helps me be a bit more balanced.
>
> Elly: I've been taught to take care of myself the right way. … It's working for me. So, to, to deviate from my normal pattern now … would be the worst thing I could do for myself. And I don't want to do that anymore.
>
> Randy: I eat properly, I get good rest and exercise and life is fine. … And I feel good about myself everyday and I try to keep my hygiene (up) …

Yvette's wisdom was evident as she summarized the aspect of self-talk, pushing herself, maintaining stability, and controlling the variables:

> I just talk to myself. I just tell myself … doing the housework, ah, taking care of things on a regular basis, like ah, Do you want to be like this person? No, I don't. Then smarten up, like get with it. So it is ok to laze around for a day or so, but, you know, enough is enough, and you know. Sometimes I have to be very strong willed to and I force myself to do it. …

Part of controlling the variables is to develop and utilize coping strategies for symptom management. As the OT pointed out, "over that period of time, people have developed their own tools as to how they deal with their psychosis." Distraction is a sound therapeutic technique that improves quality of life (Ritsner et al., 2003). It is taught by professionals and eventually used independently by people as they develop insight:

> LSW: We do a lot of distracting here. Do something and get their mind occupied and try and not think about things for a while, you know. And if they like to work on the computer, we will set them up, or they play games on the computer or the internet, you know. So, I am a big distracter … because it can take people from like a really agitated state and just bring them right … back to normal again.

Art spoke of how he used distraction from the symptoms:

> I find getting out of my environment that I am stuck in helps. I get out of the house, I go for a walk. … I use distraction techniques. I flip through a magazine, or watch a comedy, or watch a movie or listen to relaxing music. …

> I do art work … 'cause I remember one guy, he said, You got to get a hobby, so I started drawing again. I thanked him, I said, Thanks for that message. That is a powerful message. … So I really enjoy drawing … because C. and R. (case managers) used to talk a lot about distraction techniques.…

Distraction is a symptom management strategy for persistent auditory hallucinations (Buccheri et al., 2004; Fowler, Garety, & Kuipers, 1998). While distraction is one coping strategy for symptom management, people find ways to self-soothe as a way to manage their symptoms. Self-soothing strategies can be listening to music or using relaxation techniques (Buccheri et al., 2004; Kanungpairn et al., 2007). Owen reported that when he experienced stress and noticed louder symptoms, he self-soothed by listening to his Elvis CDs. He also reported using sports such as basketball, floor hockey, and baseball as ways to manage his illness. Peter and Patty meditated to self-soothe along with other activities:

> Peter: I am very calm, cool and collected and meditation helps me do that. … I do martial arts and tai chi and a little bit of yoga, and I can de-stress. … If I feel stressed at all, it will drive me to worry or something, I will just breathe and … and the stress goes away.

> Patty: I've been very fortunate that I learned yoga at an early age. … I've done meditation … I learned to do deep breathing. I am learning to put on tapes; uh, I learned to relax myself throughout the day.

Elly, like Art, found solace in painting and drawing, "I'm an artist at heart. … It's very healing for me to do art - art therapy." Sarah used a pharmaceutical remedy along with the self-soothing technique of finding silence, "I lay down, I take a PRN (medication that can be taken at a patient's discretion), I just go to my room and turn off all the radio and TV, and just lie in my room and feel the silence." Finding ways to self-soothe helped manage troubling symptoms.

Four Types of Insight are described within this study. The literature on insight does not furnish us with answers about how a person with schizophrenia conceptualizes

insight and these constructs help fill that gap. These constructs enable mental health workers to develop strategies and interventions to build insight capacity. Along with this development of insight evolves a new appreciation of the importance of medication.

10.3 Treatment Importance

> Henry: … then the medication all of a sudden becomes something that is a positive thing in your life.
>
> Art: … medication is a positive.

The **T** in *C.L.A.R.I.T.Y.* stands for **T**reatment importance. Registering the importance of medication took some time, but seventeen of the nineteen participants in this study reported a reversal in their belief that medication was harmful and unnecessary, to seeing medication as an important and positive influence to their well-being and quality of life. As a result of this new belief, they developed strategies to ensure fidelity to their medication regime. Lysaker, Buck, and Roe (2007) report a finding consistent with this study in that the benefit from psychiatric treatment is related to the meanings that people assign both to their illness and the treatment itself. Ng, Pearson, Lam, Law, Chiu, and Chen (2008) report that people with schizophrenia in their study did not feel that full recovery could be achieved until they "stopped medication and had a steady job" (p. 118). This attitude toward recovery is problematic as recovery is viewed as having a cure for the disease rather than the ability to have quality of life in the presence of symptoms. Ng et al. recognize the need to change this attitude. Viewing pharmacological treatment as important facilitates recovery and people in this study on insight recognized the importance of medication.

10.3.1 Importance of Medication

Carl prevailed upon this researcher to pass to other people with schizophrenia how important it was to take medication and the positive influence this has:

> … (Emphatic) you cannot forget to take your medication. Once you forget, and then you forget again, before you know it, it is not working anymore, it wears off. You got to take it every day without missing. … Somehow, you got to brainwash them to let them know how important it is to take their pill.

Elly attributed her quality of life to her medication:

> … understanding that my medication is very important to my quality of life is huge for me.

Hannah reported, "... it's much better just to stay on medication because you are farther ahead." The family member acknowledged that there was a price for staying on medication, but the benefits were worth it for her mother:

> She realizes there is price to pay for staying on … the medication. Sweety, (the medication) is really hard on my system. And it was just a sad moment for me. … There is a realization that for her to have the life she has right now, there is a price for it, and the price is that.

Patty valued her independence and Yvette the function that medication gave her:

> Patty: Because otherwise I … wouldn't be functioning as … the independent person that I am.
>
> Yvette: If I am taking my medication and my medication is where it is set at, where it is supposed to be, I function really well.

Henry was appreciative of his medication and that pharmacology had come a long way in treating psychosis:

> I mean, like in 1954, they scrambled people's brains. But now they put them on medication … very positive, very positive. And my family is happy that I am on this stuff, I see a big difference in myself when I am on this stuff.

When Irene took her medication, positive symptoms disappeared and routine was easier:

> I take medication to better control my voices, to get rid of them, to structure life more. Like it helps me get up in the morning, get on with the day, motivate me a little bit. … It takes away all the signs like hearing voices and hallucinations.

Olive expressed her relief from positive symptoms as a "blessing":

> I no longer get the voices which is a huge blessing, because when they chatter all night, you don't get any sleep, right? So they are gone and my paranoia has been lifted quite a bit … so that's good.

Norm reported similar benefits, "Yeah, it helps me think more clearly and it, it helps me get on with daily activities." Owen reported that he stayed on medication because it controlled his homicidal thoughts and he was not angry. Medication levelled him out; he did not experience anxiety much at all. Patty felt more stabilized on her medication, "This medication … it's been very good. It's stabilized my thoughts. And, uh, it gives me the chemicals that my brain needs to function properly."

Other people in the study also valued their medication:

> Sam: I realized that, hey, if this medication is helping me, then I do have a … problem, mentally and physically. I believe it works both ways.
>
> Ham: I have to take those medications or I am in deep trouble.
>
> Peter: … it does keep me in this world. … But other positive things, I guess, it is making me more normal, like if I wasn't on medications, I wouldn't quite be as … I can have a normal conversation, normal, normal interaction with people because of the use of this.
>
> Yvette: Yeah, is that I feel physically sick when I go off the medication. Yeah, I get achy all over and my spine hurts. …

A professional saw insight as the balance between side effects and knowing the importance of medications:

> RN: Once a client has insight, they also have to deal with the fact that these medications cause problems on their own … the side effects. … Sometimes there is a balance in there, sometimes we have to compromise, Ok, you can be this much sick (laughs). As long as you know that these are symptoms, and you can identify them as symptoms, and they can manage them, we can give you this much less medicine.

Ingrid hated the side effect of weight gain from her antipsychotic medication but would not trade her medication for being thin:

> If I had to trade being thin … trade my sanity, to be a thin beautiful woman, I will take being a fat woman, thank you, because that is how much my sanity means to me.

Randy was dramatic about why he takes his medication, simply stating: "To live, to be sane!"

People in the study did not achieve complete eradication of their symptoms. Many continued to struggle with both positive and negative symptoms, despite being on medication. Complete eradication of symptoms using antipsychotic medication may come at "an unreasonable cost of life threatening adverse effects or stigmatizing side effects" (Lakeman, 2000, p. 524). People in the study had come to accept this fine balance between side effects and ability to function and to appreciate that medication was available to assist them to function. This appreciation was evident in the measures that people took to ensure they remembered to take their medication.

10.3.2 Strategies for Fidelity to Medication Regime

Once people recognize the importance of medication, they work hard to find ways to ensure they stick to a medication regime. Henry reported his strategy: "I just do a week's supply at a time." Carl shared his strategy: "… then you got to take your medications, every day, without missing." Elly made a commitment to not go off her medication and to avoid marijuana, "… finding the strength to stay on it and to stay off pot, too."

Blister packs were popular strategies:

> Patty: Thank heavens for that blister pack, because there are days sometimes I get up in the morning and I think, did I take my pills? … If I didn't have that blister pack, I would be overdosing myself.

> Ham: I have blister packs. … I always … carry my pills in here (pulls them out of wallet wrapped in tissue), pills right here. … I have to take these pills every day.

Hannah liked the convenience of blister packs, "like I take food with me and water to try and take with the pills. … It is more convenient, instead of messing with the pills all the time." Olive was "religious" about taking her pills on time, "No, I am quite religious about taking my pills."

The influence of other illnesses has an impact on medication adherence. The family member quipped, "Who would have thunk, mom, that your epilepsy would have been your saviour, because it got you into the routine at a young age." The influence of other illnesses and pairing medication response and medication regimes also strengthened fidelity to medication. Carol explained:

> In Europe, when I was younger, I was highly asthmatic and had to go to hospital. I got a needle in the butt. After that the asthma seemed to settle down. I guess there is a parallel: you get a needle, you feel better. It helps me stay mentally straight, to take my pills.

Olive, Patty, and Henry took medications for physical health reasons and this reminded them to take their psychiatric medications:

> Olive: … then all of a sudden I feel dizzy, and, a, shaking, and all that and my diabetes. And then I realize I forgot to take my 9 o'clock pills. So I run to the back and take them, but I never miss them.
>
> Patty: … because they are timed with my epilepsy, then I think, did I take my pill?
>
> Henry: … so now that I have cholesterol pill and I got a vitamin and stuff.

This is strong evidence depicting how people with insight have come to view medications positively, and how they work hard to adhere to their medication regime in order, as Randy said, to stay "sane". With the recognition that medication is

important comes a full yielding and acceptance that they have a disease called schizophrenia.

10.4 Yielding to the Illness

> Psychiatrist 2: I mean, are we talking about someone appreciating that they have schizophrenia or someone appreciating that they have to make a lifestyle change that goes with having a chronic mental illness? And those are probably facets of the same polished piece of glass.
>
> FM: Our family has accepted it. It is not like a hush, hush, dirty secret. It is not like she is the black sheep of the family. … We all don't … walk on eggshells. … It is just another part of our family's mosaic of interesting people.

The **Y** in *C.L.A.R.I.T.Y.* stands for **Y**ielding to or accepting the illness. The degree of acceptance is on a spectrum from partial acceptance to full and complete acceptance of the illness. Carol was ambivalent, even in her acceptance:

> First, I don't accept that I have schizophrenia. Ok, I accept it, ok, but it is complicated. … I guess I am schizophrenic, but I don't like the label.

Randy had absolutely no ambivalence about the diagnosis of his illness, **"**Well, if it is not schizophrenia, I don't know what the hell it is (laughs)." Ham believed he is not a heavy duty case, "Well, no, no, I am not schizophrenic, but just mild, that is all Dr Z. said, I am just mild, not heavy duty, I am just mild." Norm accepted he had the illness, but wished, in some way, he did not have to admit to his illness:

> Yeah, it's any diagnosis is serious, but, uh, for the most part I accepted it. But, uh, in some strange way, uh, I, I wish I hadn't (laughs).

Sam's acceptance got the "monkey off his back":

> It's a monkey off your back. You accept that you have an illness, and it takes the monkey off your back. … After so many years, I finally understand that I have schizophrenia. It's a very, very, very difficult word, uh, very difficult to understand at first. You don't feel like you're a part of schizophrenia, but after a few years, you realize, Hey, I really am who I am, and I am schizophrenic.

Ingrid's acceptance evolved:

> I am not sure … when I really came to terms that I had a mental illness. … I think it was just an evolving thing.

Carl gave advice about accepting the illness:

> … you will be a schizophrenic for a whole lifetime, you got to accept it. You got to accept the fact that the disease won't go away, that it is going to be with you for a whole lifetime. And you got to face up to reality, what you are up against.

Hannah's statement of acceptance contained a tone of realization, "This is real, the illness is real." Owen reported he had accepted that he had schizophrenia, because there was nothing he could do about it, but hoped for a cure for others and himself. His acceptance was difficult due to the stigma and fear that he would be ridiculed and shunned by others. Peter knew he could not run away from his illness:

> It is just part of my life. I just accept it … so I accept it. … You just have to surrender it before God and say this, I will go through this, right?

The family member felt that her mother's acceptance of her illness was related to others' acceptance of her:

> I think part of that is from my total acceptance of that. … Everyone is just so proud of her. I think it is a catch 22; they are proud of her because she has this amazing attitude about it, and she has this amazing attitude about it because her friends accepted her because of it, her family accepts her.

The LSW saw acceptance as necessary for higher functioning:

> … people who are higher functioning … I would say they probably know that they have a mental illness.

There is a chicken and an egg quality to the following quote, begging the question as to which comes first, acceptance, then control, or control and then acceptance:

> OT: … when I talk about somebody who has insight, that is their accepting that they have an illness, and they know when symptoms come up and they know how to deal with them. … I think it is, it's accepting. Once somebody has accepted that they have an illness, then they seem to be more open to learning about, maybe, how their lifestyle at the moment needs to be altered a bit.

Elly summarized her acceptance:

> This illness, that we call an illness. That could really be some sort of gift. We don't know, um, you know I've come to terms and peace with it.

Yielding and accepting the illness comes at a high price that is paid through learning the hard way, medication trials, side effects and the stigma. This yielding into acceptance is the transition point, the change in circumstance that moves the person forward in the process and beyond the illness. From it flows a period of calm, tranquillity, and quiet: a *Period of Wisdom*. Paradoxically, it is this yielding to the illness that creates the potent force that builds wisdom, tranquillity, and protection from relapse.

10.5 Conclusion

This chapter has concluded the *Dynamic Period* and completes the ITY in *C.L.A.R.I.T.Y*. Developing **I**nsight contains *Four Types of Insight.* These types of insight may provide mental health workers with new intervention tools for assisting people with the illness to develop insight. It is hopeful that people with the illness do begin to recognize the importance of **T**reatment and to finally accept or **Y**ield to their illness. This acceptance and yielding to the illness is what, paradoxically, allows them to develop wisdom about their illness. Chapter Eleven describes these final stage of insight development, the *Period of Wisdom,* wherein people with the illness become comfortable enough to begin to speak to others about their illness, are able to acknowledge their strengths, and find meaning and purpose in life. The chapter then describes how they are able to integrate the illness without being engulfed and disabled by illness and concludes with a description of how people sustain their wellness.

CHAPTER ELEVEN THE PERIOD OF WISDOM

11.1 Introduction

This chapter describes the last stage of insight development, which is called the *Period of Wisdom.* Wisdom arrives, paradoxically, after the eventual, gentle yielding to a disease that has held great power. Wisdom evolves out of the *Dynamic Period* and from wisdom flow self-actualization and improved quality of life. Research on schizophrenia needs to move beyond its focus on the mere control of psychotic symptoms to include functional recovery and quality of life (Leucht & Lasser, 2006). Reaching the *Period of Wisdom* is to claim a functional recovery even though this recovery of function may include continued chronic symptoms. Important dimensions of quality of life include physical and mental health, a degree of independence, social relationships, and characteristics within the environment (Puschner et al., 2006). The resolution of difficulties in these dimensions converges in the *Period of Wisdom,* and four components contribute to this wisdom: talking about the illness, finding some meaning and purpose in their lives that gives peace and contentment, integrating the illness and sustaining the wellness. These four components are discussed in this chapter.

11.2 Talking about the Illness

> Olive: … everybody has a story; everybody has a story.
>
> Hannah: I have made myself a pioneer about being open and honest about my diagnosis and medication, because, I am trying to help remove the stigma by putting a face on schizophrenia.

As people develop insight and wisdom, they are less reticent about disclosing their illness. They begin by telling their story through self-disclosure, recognizing their strengths, values and personality styles, and giving expert advice. Telling their story is a public declaration that they are a person with the illness, and in some way, this public declaration leaves behind the stigmatizing effects of the illness. Taking its place are a new pride and recognition of values, strengths, and aspects of personality that are not robbed by the illness. Talking about the illness also includes passing advice onto others starting down the road of the illness.

11.2.1 Telling My Story

People who affiliate with consumer groups and publicly admit this relationship are less overwhelmed by the stigma and feel more in control (Corrigan & Wassel, 2008). This "coming out" (p. 47) is described as breaking the secrecy. In this study, personal decisions dictated the participants' methods of telling their story: through selective disclosure, indiscriminate disclosure, or broadcasting on a grander scale. To benefit others, Art shared his story selectively:

> I don't divulge to all the clients that I am schizophrenic, only to a few that I feel would benefit from it.

Carol was also selective about to whom she self-disclosed, "I don't talk a lot about my illness to people, but I am not hiding it." As she gained wisdom, Elly would talk about the illness in more objective, depersonalizing terms, "I don't let it control my life anymore, so I can talk about it objectively." The family member did not hide behind a curtain of secrecy either, and in fact, took pride in her mother's successes in battling the illness:

> I am … very open about the fact that my mother has schizophrenia. … I used to do a lot of public speaking around being a daughter of a mother with schizophrenia.

Hannah, Ingrid, and Art talked about their experiences of helping others:

> Hannah: I think that what I do … is help people through my experiences … because people have known that I am schizophrenic. … I have made no secret of it…
>
> Ingrid: But I never hide my mental illness … doesn't mean that you can't be a valuable person and contribute to society.
>
> Art: I still think that I have helped thousands of people. … I was speaking at NA (Narcotics Anonymous) conventions and stuff. I would talk about living with a mental illness and staying clean, and I guess I gave a lot of people hope.

Randy talked of his earlier reluctance to disclose to others that he had schizophrenia, but admitted that time was making him more comfortable with disclosure:

> There are some people that I have told, about my schizophrenia, and stuff like that. And, um, I am more open to it, more willing to talk about it more, as before I was quite embarrassed. … Over the years my mind has changed a lot towards things.

He agreed to speak to this researcher about his illness for two reasons: to advance research on schizophrenia, and, therefore, to help himself. Henry and Irene also valued the opportunity to speak to the researcher as a way of telling their story:

> I have always wanted to, me and Irene … to get our story on paper, and maybe one day, something will come of that.

Pulling aside the curtain of secrecy and shame required courage and strength but brought relief that they could finally be more open about their illness. Unburdened, they relished their strengths and values that remained intact, but were, perhaps, obscured for several years.

11.2.2 Acknowledging My Strengths and Values

> Psychiatrist 2: Carl Jung said that psychiatry is the celebration of the human resilience and if the human spirit wasn't resilient, psychiatry wouldn't have existed.

The Strengths Model of Care Management for people with mental illness is a set of principles and values to assist people to recover, reclaim and transform their lives through their unique strengths, talents, and skills (Rapp & Goscha, 2006). Individuals have hidden reservoirs of "physical, emotional, cognitive, interpersonal, social and spiritual energies.… These are invaluable in constructing the possibility of change, transformation and hope" (Saleebey, 1992, p. 6). Further, Saleebey suggests that client motivation is based on fostering client strengths. As people begin to recover, their ability to acknowledge their strengths emerges and consequently, their self-esteem begins to build.

Hannah's self-esteem was based on experiencing healing, "it has badly damaged what self-esteem I had. … I am healing from it." Irene expressed this same theme, "value myself, feel good about myself, like I think when I was first diagnosed, I didn't think anything was good." As did Randy:

> I have always thought I was stupid. I never thought that I was smart, um, but then one day, when I started doing things on my own and succeeding in little things, maybe I am not stupid.

Olive's self-esteem developed so she could see her personal worth:

> … building self-esteem is very important and building confidence in myself, and there is just so much to learn. … But I am starting.

Within that process of rebuilding self-esteem, people begin to recognize their strengths. People highlight some of their strengths that allow them to cope with their

illness. These include personality qualities, intelligence, a sense of humour, and social skills.

People in this study spoke of their personal qualities. Sam simply believed in patience, "Patience, lots of patience." Others articulated their personal strengths:

> Norm: I was always optimistic. … Probably my strengths are my perseverance and, um, I always try to work on … my goal to make myself more perseverant. You know, to stick to it.
>
> Elly: (My parents) taught me about integrity and speaking the truth. They taught me about being strong, … a leader … being brave again … not being a coward.
>
> Carl: I am quiet … I compromise with people, I'm gentle with people, but I'm no fool, I am not a fool, I am careful.
>
> Carol: My strengths are that I am a strong woman, I listen to people, catch myself listening to people, and I learn something when I listen.

Intelligence appeared to be a strength. Zack credited his intelligence as his best coping feature. Hannah valued her intelligence, "I am not what you say, an A student, but I got brains that I can use." Intelligence appears to be a factor in recovery. Tyson, Laws, Flowers, Mortimer, and Schultz (2008) found that executive function (planning, sequencing, initiation of behaviour, self-monitoring, and inhibition of behaviour) (p. 112) plays an important role in social functioning and quality of life.

Having a sense of humour was viewed as a strength and people relied on their sense of humour to cope with the illness:

> Olive: Oh, humour, I love telling jokes and I love smiling. Oh, for heaven sakes, I love smiling, right? I think about Mickey Mouse. With the black ears, you know. I think some of the flowers are just comical, so, I try and look at things on a lighter side …
>
> Sam, That's who Sam is. Humorous, yeah. I like humour. It keeps me out of trouble. … That's where humour comes in.

> Patty: I think it has a lot to do with a good sense of humour of things, you know.
>
> FM: … sense of humour, you have to have a really good sense of humour.

An example of humour was evidenced in the final focus group of participants. Art told a funny story and the group roared with laughter:

> I was at the hockey game, and I saw Dr Y. I said, Dr Y., can you give me a pill that will stop me from looking at women? And he goes, Yeah, but it will make you really depressed (laughs).

Humour-based interventions can be beneficial to patients with chronic mental illness, and the multiple mechanisms by which pleasure, play, and positive life events are encouraged can promote recovery (Taber, Redden, & Hurley, 2007). Humour may also be a method to evaluate and/or study social cognition in clinical disorders (Corcoran, 2008). In addition to a sense of humour, social skills are also identified as strengths.

The prodromal stage of the illness often interferes with normal social development and robs or at least hinders people's ability to develop social skills (Fonagy & Target, 2003). Elly valued her social skills, "So I'm really lucky that I'm able to blend. I am able to blend back into society, which is nice." Irene and Henry valued their social skills as well, "… we have always liked company, to sit and talk … that really helped (us)."

People were able to acknowledge and talk about their personal strengths and values, markers of a returning self-esteem. This development of self-esteem and confidence gave them the right to offer advice to others and to embrace the future with a growing awareness of their own "potentiality". "The notion that what you seek or desire is achievable through an awakening of a sense of personal capability and the ability to

seek out opportunities to change" (Onken, Dumont, Redgway, Dornan, & Ralph, 2004, p. 12).

11.2.3 Giving Advice

Talking about the illness has underlying motives for people: to dislodge the stigma, to educate others, and to drop the veil of secrecy that has pervaded their lives for many years. People in the study wanted to spare others the pain of the illness and had advice to offer others who had the illness. This advice included learning about the illness:

> Art: … to learn about it, ask questions, take your meds, be honest about the side effects of the meds because they may be able to find one that suits you. Ah, I think the biggest part is educating yourself. There are a couple of good agencies like the BC Schizophrenia Society, there is different courses you can take to learn about it.
>
> Yvette: I would say, listen well to what your friends, your family… have to say. … They can give you a lot of information if you are going to receive it; being willing and open mind to receive help that is there before you get into a situation where you (end up) in the hospital.

The importance of medication was discussed in Chapter Ten, where the people in the study offered advice to others about taking medication:

> Carl: … you got to take your medication.
>
> Carol: Take your medication, believe in yourself, and don't let too much anxiety get in the way.
>
> Randy: I would say listen to your doctors, and stay on your medications. Those are probably the two biggest, that's the two biggest ones for me.

Henry, Elly, and Olive stressed assertiveness to find the right medication and to get needs met. Olive summed up this theme well with this advice:

> I think what newly diagnosed people should try and do is speak up; people can't read your mind, and the only way to get your needs met is to speak up, and another thing is learn how to say no.

Many offered suggestions to provide comfort and reassurance to others facing the fear that often accompanies this diagnosis:

> Elly: I would say don't be afraid, number one. There's nothing to be afraid of. You're safe, um, it's going to get better. It's going to get better with your help and we'll work as a team, we will work together, you're never alone …
>
> Ingrid: I would say to have faith that you will get well, believe that a normal life is possible, cause it is …
>
> Olive: Um, not to be afraid of it, definitely not to be afraid of it … because if you educate yourself it liberates you, because you are no longer afraid of the unknown. … Don't be afraid, jeepers, don't be afraid. … You got schizophrenia, ya sure, it's too bad you have it, you know, but you can live with it …

Talking about the illness allowed participants to acknowledge their strengths and provide advice to others. Talking about the illness released the pressure of storing the secret for so many years of silence; it weakened the power the illness had over them. As their illness had less power, they found increased meaning and purpose in life and were evolving toward fuller integration of self.

11.3 Finding Meaning and Purpose

> A closely related step in the process of growth for participants appeared to involve developing an internal sense of meaning and purpose. (Roe & Chopra, 2003, p. 342)

Existential theory eschews deterministic views of life and emphasizes that people have the freedom to choose how they interpret or make sense of their given situations (Fernano, 2007). This freedom includes creating their own reality and their own meaning in life, thus, giving them direction and structure (Krueger & Hanna, 1997), as well as the potential to improve. Meaning and purpose in life for people with a psychiatric illness involves the ability to "pursue and undertake productive activities of interest, such as education, employment, hobbies, family life, parenting, intimate

partnerships, community involvement and activism" (Onken et al. 2007, p. 12).

Finding meaning and purpose in life both facilitates and indicates personal growth.

Elly felt her illness had given her purpose and direction:

> Well, like I say, I don't necessarily like to view it as an illness because maybe it's giving me a purpose … to maybe reach out and help other people. … There may be positives with illness, or gifts.

Olive also identified giving support to others with the illness as a way to find meaning and purpose:

> I would like to find other ways of helping, other consumers with schizophrenia to cope … and help them with the knowledge that I have gained.

Hannah, Ingrid, and Olive were not yet able to articulate their meaning and purpose but believed one existed for them:

> Hannah: Oh, yes, I may not know what it is, but I know it is there. It is still going.
>
> Ingrid: I have evolved into a well-rounded person that can get along with mostly anybody. I wouldn't trade it and it sounds really weird, but Paul the apostle said that all things work for good for those who love God and are called according to His purpose. And what that purpose may be I don't know for myself. But all I know is that I have been.
>
> Olive: Well, my God, I would say He had a lot to do with it, because He always tells me that, life is, you are here for a purpose – discover it, you know. So I am wanting to find out what my purpose is and, um, live it.

Owen's paper route provided him with meaning and purpose and he took great pride in doing a thorough delivery job with no mistakes. He received positive feedback from his customers that reinforced this purpose. The LSW also saw that volunteer work provided meaning and purpose:

> … we have … community volunteer programs … in the hope that that person will then take that job experience and then move out into the community.

Many examples of volunteering provided meaning and purpose:

> Ingrid: … just because you are schizophrenic … doesn't mean that you can't be a valuable person and contribute to society. Because I have done tons of it in my 24 years of volunteering and you name it, I have done it.
>
> Carol: … I volunteer there three days a week. I help feed the (elderly) people that shake … so I volunteer. … On Bingo Wednesdays, some of them can't see the large numbers, so I point to where they are and they are very happy. … So I get a thrill just watching them win, right?
>
> Patty: Yeah, I donate at least 40 pairs of winter socks to St. Vincent de Paul every year … do facecloths. I, uh, some of my baby blankets go to the (police) for the children that have been abused. … When I tell my daughter I wish I was working, like I used to, she says, but you are working!

Achieving goals and helping others gave Irene meaning and purpose:

> I am setting some goals and getting on with getting them concluded, I feel the future holds some promise to me. … I still have tons of things that I got to do before I go, more to give and more to learn.

Henry worked at his home-based business:

> I think that it will be even better because I got involved with Community Futures. … They are helping me with my (home-based business).

Service to others, goals and work imbue life with meaning and purpose, deepen relationships and lend hope that more benefits and blessings are yet to come. Being more open about their illness whilst enjoying enriching life experiences creates actualization of the person and a fuller integration of the illness into their self-concept.

11.4 Integrating the Illness

> FM: … she is not going around saying, I am schizophrenic. She is P. who has epilepsy and schizophrenia and also who sings at a drop of the hat, laughs at a drop of a hat. That is who she is, you know, these are just itsy bitsy pieces and parts of her, and that makes her.

As people recover, they "re-integrate" into mainstream facilities and activities, thus gaining a social identity (Bonney & Stickley, 2008, p. 146). Integrating the illness embodies a curious phenomenon. The integration described in the study is a mode of defining self in two separate ways, much like two sides of the same coin. Firstly, there

is an integrating or assimilating quality where the person integrates the illness and embodies it within their self-concept; they have schizophrenia: "I am schizophrenic". Insight and a coping style that "tends toward integration of the illness rather than sealing over and disregarding it are critical to adjustment to the illness" (Wittmann & Keshavan, 2007, p. 154). This integrating the illness experience into the self-concept is a critical component of the recovery process (Jacobson, 2001).

Yet, curiously, there is another side to this coin; a separateness from the illness, a distance that suggests a mosaic quality, a separateness from self. This mosaic quality says, I am Patty, I am Sam, I am Henry first *and then* I am a person with schizophrenia, "replacing a view of self as centered on a psychiatric disability to that of one who is a whole person facing challenges" (Onken et al., 2007, p. 13). The illness is separate and apart from them, and they do not allow it to define them. This may be a common theme in people with disabilities. People First is an international organization that advocates for people with developmental difficulties. Their motto is, "We are People First and our disabilities are second" (People First, 2006, p. 5). This motto assists those with disabilities to recognize their humanity before their disability. This recognition is part of integrating the illness. Integration signifies a quality of life indicative of self-actualization.

Henry, Norm, and Sarah explained both the assimilation of the illness and the mosaic aspect of the illness:

> Henry: Well, I am different than anybody, sometimes I feel, sometimes with the illness, I am different. But I know in my heart when I think it over and over again, I am just like anybody else.
>
> Norm: I have integrated … and probably still integrating. … Yeah, I have schizophrenia, but, you know, I can also do other things and have talents and respects as well.

> Sarah: I don't let schizophrenia hold me back, whereas some people will say, well, I can't do that, I am schizophrenic and I can't do that. I don't do that. I do whatever I want (laughs), you know, I am not going to let an illness boss me around. I don't let anything hold me back.

Ingrid had schizophrenia, but she was also a wife, mother and grandmother, "I think I am fairly well balanced, ya, I really do. And I am happy with my life, I have a good husband and wonderful children, nice little grandson." Hannah reminded the researcher that while she was a woman with schizophrenia, "I am a Christian first".

There is another way of looking at the same coin, while still reflecting on its two sides. Both Irene and Henry recognized while there was loss there were also compensations:

> Irene: No, because I like me most days and I like what I do. And I feel like I contribute to the world, or to my friends, or something or to myself. And I look back, if I did lose anything, it is ok, too; maybe I wouldn't be happy with what I would have gotten.

> Henry: I suppose everything has its pros and cons. … Financially there is loss, but the other things, morals or ethics or friendships or relationships, there is gain, right? Um, like I could have ended up doing something at the end of the day that might not have been good for society, or people kind, and um, that would have been no good, right?

Norm and Carl summarized this loss and compensation theme with humour:

> Norm: I was meant to have one thing or the other. I was meant to either have a career on one hand, or else family life on the other. … They say, you know, I've had money and no honey, or a honey and no money (laughs).

> Carl: I am 65 years old; I realize how lucky I am. I've been single, not being married, not having children, lived alone all my life. I feel that I was pretty darn fortunate to have such a good life, to live alone, without getting married, not having children, having a big car, having a job. I got away from all that by living alone.

Elly was grateful for the miracle that she had stayed alive and was exuberant about her painting career:

> Mmmm, maybe because it's a miracle that I'm here alive today. Now that I'm coming out of the other side of it, I want to learn, learn, learn, learn, learn. I

> just want to know how the world works and now how candy corn is made. … Learn how to use a level to hang my pictures, or just learn new things. Um, I guess God, God, I guess my natural talent as an artist, and you'll see in my paintings.

"Carpe Diem" may be a theme of this integration:

> Olive: I am thankful and then I jump out of bed and its like, alright, what am I going to experience today?
>
> Randy: … take it one day at a time, live through the day and go to bed and wake up. And hopefully have, some days are so, so good that I don't want to go to bed or go to sleep, I want to stay up and … enjoy it!
>
> Irene: I have come a long way. … I want to live a lovely life. It is too good to be wasted!

Irene felt that full insight and integration was, "when you have peace within yourself". Randy did not feel the world owed him anything, "No, no, I don't feel sorry for myself one bit, ah, I don't, the world doesn't owe me anything, um, nobody owes me anything. I am just trying to go on with everyday life." Patty had been a ballerina before the disease struck her, but she had no regrets about her life:

> My older brother … said to me, Who did you really want to be in life? Well I did 12 years of ballet. I went to the Winnipeg Ballet and I really enjoyed that. And he said, What would you like to be doing now? And I said, Probably exactly what I am doing.

Patty can laugh at her brother's teasing at her return from illness:

> Well, you know that my older brother … patted me on the back and said, It's so great to have you back from La-La Land (laughs).

Integration is at the end of a long road that achieves the self-transformation from "patienthood" to "personhood" (Roe, 2001) and thus, finally, externalizes any stigma. Integration comes as a result of a long *Period of Chaos*, followed by the *Dynamic Period* of *C.L.A.R.I.T.Y.* where insight was developed, and is at the end of the *Period of Wisdom*. Integration may be the rewarding outcome of an individual's tenacity in facing the trials that both raise and dash hope during the recovery process. Integration includes the ability to sustain this wellness, and is, really, a re-integration of the

person back into the normal human experience of life. Because the road to recovery has been so long, people work hard to sustain the wellness.

11.5 Sustaining the Wellness

People in the study were asked about their worst fear. It became evident that the worst fear may actually have been sustaining their wellness. At first this appears negative and tragic, but avoidance of a negative experience may be what human beings do to keep safe. Stating our fear (negative energy) is also a way that we imply what we really want (positive energy). For instance, a fear of obesity may motivate a person to exercise and/or maintain a healthy diet, as safety is found in having a normal, healthy body. A fear of a heart attack may be the motivator to live a healthy lifestyle. Safety is a sound heart. The fear of being sick again is not unfounded in mental illness. Fear keeps people vigilant about their illness and maintains the positive goal of wellness. The *Fear Factor* is a protective factor.

Ham and Randy had identical fears:

> Ham: I am fearful that I will be killed in the world today.
>
> Randy: … that I am going to get killed. … So tied up in the voices and trying to explain to them not to kill me, and not get people to kill me, and do things to me, or take me against my will, and not let me go and take me, beat me or whatever, ‘cause that is what the voices tell me.

Irene, Art, Yvette, and Peter feared permanent relapse and institutionalization:

> Irene: That I am never going to get better, and I am going to get so sick, and I am going to end up in (hospital) is my worst fear.
>
> Art: … getting so bad with psychosis that I never come out of it. … Sometimes it is traumatizing. Like, my last psychosis was very traumatizing. I don’t think that I ever got over that.
>
> Yvette: I do have a fear of relapse … ended up back in hospital and I don’t want to be there. … The loss of control more, so scares me, and I never want to be there, I have had a few bouts, and, no, I don’t like it.

> Peter: I would take any measure, humanly imaginably possible, to not go to hospital. … Do things just so that I never had to go to the hospital; I do anything to not go to hospital.

Randy remembered the pain of the illness, "that deep hole … the emptiness and the hopelessness is the worst feeling you could ever have, the way I see it and I don't want to fall in that." Sam feared being rejected by society, "Being cast out as a normal human being." Henry feared delusions and the shame of not recognizing he is delusional:

> … that I might, you know, think that I am a football player and walk around telling everyone that I am a football player, when we all know that I am not a football player. … I just have to go by the grace of God that my mind kind of stays in control, eh?

Carl remembered being, at best a nuisance, and at the worst, homicidal, and this kept him safe from relapse:

> I don't forget any more. … You are messy, you are dirty … causing lots of problems, if you are sick. … Now, if you can remember that when you get sick, you'll be alright. … hurting someone; taking a gun or a knife and killing someone. That is my biggest fear about being sick. That's why I don't want to be sick.

Hannah and Zack also feared hurting someone:

> Hannah: Killing someone. … Like, killing them, like, if they are hurt, that is regrettable, but like, they can heal and they can get better. But, like, if I killed somebody, which is possible when I am having an episode. … I lose touch with reality. And I've hurt people before and I've destroyed property.
>
> Zack: Zack doesn't want to go to jail again. Zack doesn't want to hurt anybody, but if Zack feels threatened, then Nitro (Zack) takes over. … I try to keep Nitro out of jail.

Owen reported that his medication compliance was due to his great fear that he would kill someone, be arrested, and go to jail. He also reported he remained on his medication for fear that if he became violent, his family would reject him for spoiling their trust in him.

This "spoiling of trust" was identified as a common theme of danger:

> Henry: I don't play around with that. … It is a strict no, no. Do not go there, I have been there about three times now, and, ah, it's much better just to stay on medication because … you can spoil the trust of people.
>
> Irene: I promised my mother I would never go off my meds because I didn't want her to worry any more.
>
> Elly: I don't want to lose him, because I am happy with him. … That is my promise to myself, um, my promise to my parents and to people that love me. Um, almost losing me three times, um, it's played a huge part in hurting a lot of people, including myself.

A psychiatrist agreed that motivation to keep well was relational:

> Psychiatrist 2: See, if you can have that relationship, that trust, that reason why someone wants to do something for you or for themselves in relationship with you, that is often the strongest motivator. … So, perhaps, the biggest motivator for people to change is because they perceive that they will either lose, or maintain, or gain a significant relationship.

Interestingly, many of the *Fear Factors* that maintain wellness mirror the fears of the original events. The fear of the original event provoked the road to wellness and the very real fear of a relapse prevents a road to relapse. The *Fear Factors* exist and, like sentinels, stand around the *Dynamic Period* and the *Period of Wisdom*. At one end of the process, fear is an instigator of change, and yet, at the other end of the process, fear is a defender of wellness, recovery, and freedom, and prevents relapse. Fear is a protective factor and may be what prevents being caught and pulled back into the swirling forces of the *Period of Chaos*. This is supported by Hodgins and el-Guebaly (2000) in their study on gambling recovery where the fear of financial loss is real and must be maintained in order to avoid relapse, "Common cognitive motivational actions included recalling past problems … and anticipating future problems" (p. 17). Evidence from the data in this study demonstrates that this fear protects from relapse.

Articulating for the researcher what insight was for them and explaining how they arrived at insight and recovery was difficult for participants. An elusive and mysterious quality exists in the process. Ingrid tried to explain:

> There will always be some mystery in it and somebody told me once that maybe you are not meant to know. Maybe it is something you will never know, but maybe you just carry on with life as best you can.

This lack of explanation is perhaps an edict and expression of the complexity of the illness and the complexity of the individual vis a vis the complexity of the Western social construction, the complexity of the environment and the relationships contained within that environment. Grief and loss are regarded as an existential process and can be transformative (Kumar, 2005). Our attitude and response to suffering defines our present and our future.

While the course of the illness over the first two years is predictive of the long-term course, Warner (2007) believes this should not automatically give us grounds for pessimism in cases where the early course is poor, "One-fifth of those who suffer a poor, early course recover later in life" (p. 1444). In fact, embedded in the data found in this study is evidence supporting other studies that insight development does exist. Indeed, people can and do gain mastery over their illness, which is a hallmark of recovery (Onken et al., 2007). This mastery does not mean a cure or the absence of symptoms; most have ongoing symptoms. Mastery means a recovery that, in spite of ongoing symptoms, yields a positive sense of self and the ability to surmount the social impact of the illness (Onken et al., 2007).

Mastery gives the sense of not only surviving a mental illness but also thriving in spite of the illness. When individuals rebuild their lives with qualities that exceed

those they had prior to their difficulties (Cook & Junkies, 2002), or when their experiences of traumatic life events lead them to become better than they were before (Carver, 1998), thriving occurs. People in this study described prodromal problems that led to developmental arrest early in their lives. They survived years of chaos, and throughout the *Dynamic Period* tried to regain lost ground. Yet, the wisdom attained seemed to exceed any developmental stage from the past. Participants have not merely survived but have lived to thrive.

11.6 Conclusion

This chapter has described the *Period of Wisdom*. Wisdom arrives, paradoxically, after an eventual, but gentle, yielding and submitting to a disease that has held great power. Wisdom evolves out of the *Dynamic Period* and from it flows self-actualization and quality of life. Different dimensions of quality of life are important in everyday life including physical and mental health, degree of independence, social relationships, and characteristics of the environment (Puschner et al., 2006). These dimensions appear to converge in the *Period of Wisdom*. There are four components that contribute to this wisdom. In this period of wisdom and calm, people break free of the stigma by talking about the illness, finding meaning and purpose, peace, contentment and integration of the illness, and by using fear to sustain the wellness.

This chapter has also concluded the process to insight development and recovery. Recovery is not static, but, rather, fluid and is seen uniquely as part of the ongoing personal journey (Bonney & Stickley, 2008, p. 149). Wciorka (1988) introduced six "attitudes" people may have about their illness relating to insight. These attitudes pertain to the patient's sense of their illness belonging to them, having influence over

their illness, the location of the cause of their illness, the ability to evaluate their illness, the readiness to discuss the facts of their illness, and, finally, the effort to develop a concept of their illness. The process of insight development allows these attitudes to form and become embodied within the psyche of the person with the illness.

A continuum or process of insight development does exist. The most widely used instruments for measuring insight view it as a continuous process, composed of multiple dimensions. The voices of the participants in this study have shone light on this process that contains three core stages or sequences. The continuum begins with the "sealing over" and denial during the *Period of Chaos*, which leads to the *Dynamic Period* where *C.L.A.R.I.T.Y.* develops and action against the illness is taken. Finally, wisdom and integration occur in the *Period of Wisdom*. *Four Phenomena of Influence* permeate and influence the process of insight development and are the focus of the following two chapters.

CHAPTER TWELVE FOUR PHENOMENA OF INFLUENCE

12.1 Introduction

Surrounding the process of insight development and recovery are four phenomena with influencing and impacting properties. Paradoxically, these four phenomena have the potential to both facilitate and impede the process. The *Four Phenomenon of Influence* are: losses, barriers, relationships, and God. The phenomenon of God was a surprising finding with the majority of people referring to a diety. Spirituality, therefore, is deserving of its own chapter and will be discussed in Chapter Thirteen. The evidence for the first three phenomena is presented and discussed in this chapter.

12.2 Losses

> There is a need for the person experiencing the loss to suspend defensive responses long enough to experience the powerlessness that comes from not being able to restore the past. (Wittmann & Keshavan, 2007, p. 157)
>
> …dominant themes in narratives by individuals with schizophrenia included psychic pain, intertwined with themes of lack of control, failure and loss. (Lakeman, 2000, p. 524)

Lewis (2004) coined the phrase, "usable insight". This is insight based on an "accurate perception of what has been lost which then determines how one might go on into the future with a realistic appraisal of one's situation" (Wittmann & Keshavan, 2007, p. 155). These losses include the primary loss of cognitive and emotional functioning, but also secondary losses of independence, education, vocation, and social competencies (Wittmann & Keshavan, 2007).

There is a certain wistfulness that seeps into people's consciousness stirring up feelings of loss and despair that often comes unbidden and unexpected. A temporary

re-emergence of intense grief and mourning may also occur at significant milestones or anniversaries (Rando, 1993). This re-emergence is termed "maturational grief" by Johnson and Rosenblatt (1981). Grief was expressed by people in this study as they looked back at the denial and cycling experienced in the *Period of Chaos:*

> Carl: Because I realized, when I looked back at my history, I realized that people had been telling me that all my life, and I never listened, eh? And all the trouble I got into could have been avoided if I would have listened, eh? I would have lived a whole different life, if I would have taken my medication.
>
> Irene: Ya, like, why me? Why am I picked out to have this illness? And I don't understand why God allowed this to happen. … (I'd be) probably married and have a few kids, and stuff like that.
>
> Peter: They put me in a subculture that has robbed me of experiencing the rest of the culture. And, ah, like, I don't have much money, and I can't buy a car and I can't buy a house. I don't have a family, I don't have a wife or kids. So that's been one thing that has been taken from me, I guess.
>
> Sam: It took me a long time, a long time to realize that, hey, I'm not physically fit, mentally fit, or spiritually fit to do all the things that I dream of.

Art and Ham longed for a healthy relationship with a woman:

> Art: I think the downfall of my illness is that I have not had a successful relationship with a woman, that is a hard thing to deal with. … I don't know, I think them being afraid of my illness, not understanding it.
>
> Ham: I can't talk to women, as it is hard to talk to women, because they can take you and strip you down. I have a big heart and I don't want to lose it.

Human alienation is "often most severe for those who are excluded from the labour market, left powerless on the margins without the resources to gain access to an increasingly commodified culture" (Ferguson & Lavalette, 2004, p. 307). Vocational losses existed:

> Hannah: I used to be a clerk and then a cook in the military. … Having that illness, like, put the kibosh on my plans for my life.
>
> Norm: … to a certain extent (feel the loss) … I always, always have a long-term goal to get back into it (pharmacy). And it's, and I know it's an uphill struggle and that I have to do certain things first before I can.

The losses are hard and when the memory of the losses resurfaces, there is sadness, depression, and despair that have potential to impede the progress toward recovery. "Grief and loss are not just an occasional reaction to the diagnosis but are a necessary part of coming to terms with having the illness" (Wittmann & Keshevan, 2007, p.154). In fact, recovery depends on "mourning illness-related losses, developing personal meaning for the illness, and moving forward with 'usable insight' and new identity" (p. 154). Therefore, when the losses are turned around and rationalized by a strong hope for the future, that then facilitates movement toward recovery:

> Norm: Like there is always, uh, always a flip side, eh?
>
> Art: I flip that around sometimes.

Hope "flips" or turns loss into potential:

> LSW: I think that we tend to drive our conversations around hope. Like when people are down and, you know, feeling down on their luck, or upset, … just, kind of, feeling like everything is quite negative, … we'll try to work with that person to turn it around. … Let's talk about what is to look forward to, what is the hope here … what is great out there, moving on towards more positive.

Randy and Yvette also spoke of hope:

> Randy: I do have my days, and hopefully the day gets over and I go to bed and wake up the next morning, fresh day, and start over again. ... And most of the time it is.
>
> Yvette: I am always looking for something better. You know, it is kind of like to me, ah, schizophrenia is kind of like a job, you know. If you advance … always looking for better options, a better way to go, less pills to take, less side effects. …

Ingrid offered this hope: "I would say to have faith that you will get well, believe that a normal life is possible." Henry hoped that, someday, science would find a cure for schizophrenia, "In the future somebody might come up with something." People believed there was hope in forming a relationship and having a family:

> Henry: Maybe I will get married sometime.
>
> Elly: … faith in the fact that this will be a healthy body to bear children.

> Art: I think the downfall of my illness is that I have not had a successful relationship with a woman. … I believe it will happen.
>
> Randy: Maybe I will get married and have kids, and maybe I won't. Maybe I am not cut for that, um. I don't know … I will try.

Peter and Carol also had hope:

> Peter: I have gone through things, and I haven't been able to do things. But I hope to be able to do things, and I hope to have a good productive full life, you know.
>
> Carol: I do have hope. If you don't, there isn't much point, is there?

A psychiatrist in the study believed that hope was important to recovery:

> Psychiatrist 2: Belief is one of those golden threads in insight, you have to believe.

While losses have the potential to impede the recovery process, people with insight have a way of turning this loss around to hope. Losses are innate to people with schizophrenia, but fighting the socially constructed barriers of the illness are perhaps more difficult than bearing personal losses, "recovery from the consequences of the illness is sometimes more difficult than recovering from the illness itself" (Anthony, 1993, p. 19).

12.3 Barriers

People spoke of the barriers that threatened their recovery and these barriers were largely the stigma associated with their illness. Stigma is a complex term that embodies the prejudice, stereotypes, paternal attitudes, and blame inflicted upon those with mental illness (Corrigan & Wassel, 2008). Barriers identified in the study included: society's social construction of mental illness, the expectation of others, and the stigma of poverty. These barriers exist and threaten progress, yet, somehow,

people manage to overcome them and, in doing so, facilitate their own recovery process:

> Patty: I had a teacher, she was Thalidomide and she had little arms with three little fingers. I could see, I could see her disability. But she still became a teacher. … There was nothing wrong with her brain, right? But if there's something wrong with your brain, and, like a mental illness and you're looking at Henry, and you're thinking, like what, he's a big strapping boy ... perfectly normal fellow, and you should be playing football. … I would say to people, you know, um, you know, Would you have more sympathy towards me if I were missing a limb?

12.3.1 Barrier of Social Construction

Psychiatrist 2: People view you in a different light and you are reclassified**.**

Social construction of the illness creates the stigma that arises from how society views the illness. Two psychiatrists in the study spoke of the cultural construction of the illness:

> Psychiatrist 2: I think Western culture, as much as we want to say that we are becoming more and more permissive, we are actually becoming less and less tolerant. … What was extremely unacceptable in Victorian society is actually the basis of what we base mental illness on today. … We do not diagnose diseases but syndromes … picking behaviours that we don't like … declare them as abnormal.
>
> Psychiatrist 1: … but culturally, there is this difference that has been created … you have created this culture. What purpose does it serve? Well, it lets you dominate, it lets you colonize … lets you exploit … it serves all kinds of function. You know, we create other, because we can't, you know, tolerate difference, or because there are too many people, or because there are not enough resources, or what not, and we do that on all kinds of levels.

Social construction occurs at all levels of Western society. Family, consumers, professionals, and society all have a role in shaping the person with schizophrenia's perception of their worth, competence, and place in society (Williams & Collins, 2002). However, hearing voices and hallucinating are valued and sought experiences in other cultures. North American aboriginal cultures undertake vision quests while the "matakite" is a highly regarded visionary in New Zealand Maori culture. In

addition, the lives of the Christian saints and biblical prophets' visions from God are chronicled in both the Bible and historical works (Lakeman, 2000). These social contexts construct peoples' meaning of the positive symptoms of the illness. Peter recognized these social constructions and argued that if he were in an aboriginal culture, he would enjoy status as a shaman rather than carry the stigma of a man with mental illness, "Like for me, I would be a shaman in their culture, whereas in this culture, I am a schizophrenic." Peter recognizes that mental illness can be defined by cultural context.

Many of the participants spoke of their experiences of stigma:

> Art: I don't say, well, I am schizophrenic, the stigma, eh? People think it is multiple personality or something else.
>
> Carl: Now, some people fear schizophrenics, some people, they say, Oh, he's a weirdo, stay away from him, he's a weirdo.
>
> Carol: You can't see schizophrenia. It is a label. … The label bugs me.
>
> Elly: … so this stigma attached to schizophrenia bothers me the most because I can do anything that anyone else can do.
>
> Olive: Like, when I first told people here that I had schizophrenia, What is that? Is that dual personality? Are you two different people? Or, do you have five different people in your head?
>
> Peter: It just sets up worries. … Oh, he is schizophrenic. And they leave you alone, right?

A professional in the study agreed that stigma existed:

> RN: Because stigma enters the picture, always, right, no matter what, and things are way, way, way better than they used to be, they are still humiliated. … They are hit with major whammies when they are hit with mental illness.

However, people with recovery are able to break the stigma, as described earlier, by talking about their illness. The stigma allows opportunity to educate others, to normalize the illness, and, perhaps, break up the way we have socially constructed

schizophrenia in Western culture. In addition to the stigma that accompanies the illness, people struggle with the expectations placed upon them by others.

12.3.2 Barrier of Others' Expectations

Within the barriers to wellness, the expectations of others included making assumptions and demands on the time of people with schizophrenia, and expecting them to work. Both were viewed by the participants of the study as others not understanding the very fine balance between stability and the burden of demands.

Family, friends, and community groups made demands on Irene, Henry, and Yvette for their time:

> Irene: … but they expect a lot out of me. … They don't realize I have a busy life.
>
> Henry: I think sometime, people don't understand and get in the way and expect more from you, when you are already doing as much as you can.
>
> Yvette: I am in … one of the biggest service clubs in the world, and I find … they put all kinds of burdens on me that…. They wanted me to be president this year … but I was afraid to because I thought it would be too much stress … too many responsibilities.

Social expectations revolve around work and production:

> Psychiatrist 1: So, for example, why aren't people working? People aren't working because we don't have a culture that has a capacity to offer people work that isn't in a particular structure. So if you can't show up and work for eight hours per day and take breaks at a particular period of time and have two weeks holiday and all the rest of it, we say you are unemployable? We define ourselves really by what we do. I mean the first thing you ask when you meet somebody is we ask, What do you do?

People in the study shared their experiences with attitudes toward work:

> Henry: … if (they think) you are, like, the guy who is on welfare, smoking cigarettes, and not employable, not working, well, they frown on it …
>
> Carl: Now, I would get my relatives screaming and yelling at me. My mother used to scream and yell at me to get a job.

> Irene: So, he would push me to work, oh ya. I didn't want to provoke my father and I did everything I could. … People don't understand the illness, understand how people just can't work, don't understand. And they make remarks that they are just lazy, or something, right?
>
> Hannah: … like people saying, You should get a job. Well, paid work is a little bit too much for me right now.

Despite the expectations of others about work, there remains a value, even amongst the participants, about the structure and routine of work and the social connectiveness of work. People with schizophrenia find that unemployment creates its own distress upon their lives. They experience a loss of meaningful social roles, a reduction in social contacts along with a lack of structure and routine (Marrone & Golwoka, 1999). While social contact is important, work is also viewed as an opportunity for skill development (Tausig, 1999), which, in turn, is seen as "minimizing their disability" (Mowbray et al., 2005, p. 8). People in this study found a way to incorporate some form of work into their lives, despite not being able to work full time or even part time.

> Olive: I do sixteen hours a week now. … I get a little worn out, so working here, I have been able to see what my limits are, and I can test it.
>
> Peter: I have performance anxiety at work. So, like, I try and do the best I can. People around say, Pete, just relax. … So I try to relax and I am trying to deal with work and stuff.
>
> Carol: Working was good for me, too. I pick Ginseng in the summer, and I volunteer at the Mission. I am bored, and I need to get back to work, otherwise I am spending my day waiting for (my son) to get home from school.
>
> Art: … I have a job, a dream job. It is all up to me. I can work one hour or I can work twenty (hours).

While the barriers of expectations from others have the propensity to interfere with recovery, people had found ways to adapt to these expectations through limit setting, boundaries, and assertiveness:

> Norm: I think differently now than what I did when I first got out of school. My thinking has changed. I no longer think that, you know, I have to be the bread-winner and have to work 12-hour days, and have to put in the hours, have to drive myself up the wall (laughs).
>
> Irene: … you got a job, you do this, you do that, no fun and play with it. You just come home, and you deal with the things you'd have to deal. … Now (that I don't work) it is time to relax a little bit if you can, and enjoy a little bit if you can.
>
> Olive: … and another thing is learn how to say, no. I just decide that I am not going to accept less than what I deserve. And I deserve to be loved, cared for, and have my needs met, and things like that. And I am going to find ways to get all those things, instead of waiting. I am not going to wait for people to give me these things.
>
> Sam: Other people can manipulate you … but you try not to let that happen. … You become aware of that after a while, you don't get used.

The expectations placed on them by society were disempowering; however, in the same breath, they gave opportunity to people with the illness to learn to set limits and boundaries, and to become assertive. While these positive qualities assisted them in recovery, their recovery was hindered by poverty. Yet again, they capitalized on the positive aspects of poverty.

12.3.3 Barrier of Poverty

Poverty impeded all stages of the process of insight development, but again, people were able to find a "silver lining" or a positive side to poverty. A small, but relevant finding to fighting the barriers is that poverty carries its own stigma, while being on the government social assistance program carries additional stigma.

Hannah and Henry talked about how hard it was to make ends meet:

> Hannah: Sometimes at the end of a five-week month, it gets really stressful, because I am running out of food. Because of medications I have to take with food, it gets really tough. … The government gave people like me a raise in,

> like, January, but it is long gone. … Ah, it is about $856 per month now, and in a five-week month, it doesn't go very far.
>
> Henry: … pretty much inhumane, awful, especially … the government. … They say you just fell through the cracks. … They almost make you sing, it is almost inhumane, sometime, what they do.

There is evidence that, again, people are able to turn around their reality into a positive factor. Irene was aware of the social status that surrounds money and position, but valued her personal qualities as a shield against this social expectation:

> I guess a lot of people probably don't feel that way. They have to have the big house and fancy this and fancy that. It is nice to have, but if you can't afford it, it is ok, you are still a good person. … You value life and your day, your minutes that you have together with someone, that is good, eh? It is not all money that is important.

Henry also valued commodities other than money:

> I just value things that people can't value monetary wise, like, um, you know, I can always go back to church. … I guess you could put a bit of a value on it, but my friendship, you know, the fact that Irene cares about me, loves me and that we have a good respect for each other. … I can't go and buy a new house every year and a car, but I know that I can count on Irene through thick and thin.

The attitudes individuals with schizophrenia have toward themselves and their expectations reflect their quality of life (Beck & Grant, 2008). People in the study chose values of stability, balance, limits, and health over money, status, and power. These cognitive choices are empowering and lead to recovery and improved quality of life. Stereotyping, stigma, and discrimination continue for those with schizophrenia and, in fact, recovery from social expectations can be more difficult than the psychosis itself (Bonney & Stickley, 2008). Fighting the barriers or stigmatization impacts on the process both positively and negatively. There are times when an individual is motivated by the experience of being stigmatized, and other times when the stigma becomes a hurdle difficult to overcome (Townsend, Boyd, & Griffin, 1999). Beck and Grant (2008) suggest that negative, self-defeating attitudes might be

appropriate therapeutic targets in working with people with schizophrenia. People in this study suffered from stigmatization and barriers, but coped with positive thinking.

12.4 Relationships

> Human connectedness pays a large role in the healing process and recovery … support of others in the form of relationships built on love, patience and trust are a requisite to recovery. (Onken et al., 2007, p. 17)

Cooke, Peters, Fannon, et al. (2007) report finding a link between insight and the discussion of mental health problems with other people, in particular, discussions entered in order to gather information and decide what to do about it. This relationship between the existence of insight and the seeking and receiving of support from others, suggests that people who are aware of their mental illness are less isolated. It may also indicate that those who are less isolated are more apt to have better awareness. This finding is in line with the "stress-buffering role of social support, acting as a protective moderator between the experience of stressful life events" (Cooke, Peters, Fannon, et al., 2007, p. 20). Symptoms of schizophrenia can be influenced both negatively and positively by interpersonal interaction; the type of interaction may be more important than with whom the individual is interacting (Marley, 1998). In fact, a study by Noh, Choe, and Yang (2008) found that hope in people with schizophrenia is similar to hope in people without schizophrenia; hope comes from "loving and being loved in interpersonal relationships" (p. 69). Thus, relationships have a bearing upon the hope that is necessary for recovery and to maintain recovery.

Relationships play a key role in insight development and recovery. Chapter Nine has discussed the importance of family and friends as the primary relationships. However,

people in the study also spoke at length about their relationships with professionals (the case managers and the psychiatrists). Their comments were not discussed in depth in earlier chapters, but are important and have practice implications. These relationships have the ability to both impede and facilitate recovery and, therefore, exert influence on recovery. The findings about the professional relationships are presented in this section and followed by a discussion of the relevance of these relationships.

12.4.1 Professional Support

> … the working alliance is responsible for up to 30 percent of all treatment outcomes across approaches. In working with people with schizophrenia a positive alliance is considered essential by all health professionals. (Lakeman, 2006, p. 7)

Barber, Stratt, Halperin, and Connolly (2001) list the important aspects of the therapeutic alliance as involving: support, acceptance, and affection; working together to achieve results; communication of a hopeful attitude that goals will be achieved; respect for the patient's defences; and a focus on the patient's strengths (p. 68). Professional support was deemed critical by people in this study.

Bonding the relational ties and trust is the rapport developed between the client and the professional:

> Psychiatrist 2: … rapport is rapport, it is an ingredient, a general ingredient and people either have rapport or they don't.

This same psychiatrist elaborated on this therapeutic alliance:

> I think that, initially, their role was to make contact, then the role was to guide towards recovery, and, of course, now, the role is to prevent relapse, or to keep what was obtained. And I think that is what the client wants; honest, unbiased opinions on how things are going so far. … But also, just advice. … I want to make this decision, I want to bring someone into my apartment, I want to start

> this relationship, do you think that I put myself at risk? So there is basic bouncing of ideas from other people and then, of course, trusting their response.

Professional support has the ability to influence the recovery process positively and negatively. Largely, professional support was positive for the people in this study, but there were some aspects of the support that was viewed as having a negative impact.

12.4.1.1 Psychiatrist/Physician

> Ingrid: The doctor learns about you and I learn about myself.

The physician is also central to the successful long-term management of the illness. Five elements of physician support include: therapeutic alliance, clinical assessment/education, communication, empowerment, and accountability.

12.4.1.1.1 Therapeutic alliance

> Psychiatrist 2: Unfortunately, if you have rapport, but don't have the training or, excuse the pun, insight yourself to understand what it is you want to change in this individual, your rapport for this sake doesn't mean anything.

People spoke of the rapport that built therapeutic alliances over time with their doctors. They believed their doctor had invested time in them, knew them, that the doctor had stuck by them through difficulties, and with that a trusted bond or attachment had developed. Here, data is presented to support the importance of this therapeutic relationship.

Through a self-disclosure, the OT explained how intimacy develops between patient and doctor:

> … but when I have been through something difficult, for instance labour, and my doctor helped me through the hardest thing I have ever done in my life. When I saw my doctor following that, I felt a real connection with him, a real sort of dependency or a gratefulness. And I wanted to see him more because I felt like he had seen me through my lowest time, when I had struggled, he helped me. … But he, in my mind, established himself as important and somebody that I credited my success to. So he, ah, so if it is anything like that, when somebody, a doctor or a mental health worker, has helped you through a crisis or seen you at your very worst. … I imagine there is a degree of trust and gratefulness …

Ingrid also spoke of her attachment to her physician:

> I have a good doctor, the best doctor. … I think I am attached to Dr Y. in ways. … I think that is a normal reaction from a lot of patients that have long-term (doctors).

Art acknowledged the value of his relationship with his physician, but in spite of the closeness, he was open to a relationship with another physician, should his doctor retire:

> Oh, no, I don't want to lose Dr Y. … because when I stopped seeing him, years ago, I got ill again and he said, You better continue to see me. … (but) I heard good things about Dr C. from people on the ward, people at work …

Sam understood there was some power imbalance in the relationship, but that his physician was close to him and knew him:

> So I'm, uh, not really close to the doctor. … He is close to me. He sort of knows what's going on with me, more than I know what's going on with me.

Randy appreciated his relationship with his psychiatrist:

> I don't ever want to change psychiatrists. Because Dr X. has really changed the way I think and do things and helped me out with medication, and stuff like that. And I have to say, he has invested a lot of time into me and helping me out . … Even though I see him every three or four months, but still, he has stuck by me, and he has helped me out a lot, and I really appreciate that.

Ham, then Hannah spoke of the goodness and helpfulness of their psychiatrist:

> Ham: Dr Z. was working there. I would go up to him and talk to him. … He was very good to me.
>
> Hannah: … they have been a great help, like Dr O.

Data from the study demonstrates the importance and value of the therapeutic relationship with the psychiatrist. This relationship is based upon the ability of the doctor to communicate with the patient. Additionally, people in the study valued the physicians' clinical assessment and ability to educate them about their illness.

12.4.1.1.2 Clinical assessment and patient education

People appreciated their physician's assessment skills, knowledge, and the education they provided. In addition, they valued their physician holding them accountable for their illness management.

Carl valued his physician's assessment questions:

> Now, I see my psychiatrist, and he asks me the same questions all the time. Are you hearing voices? No. Do you get paranoid? No. Do you ever think that people are talking to you? No. … He asks me all the same questions every time I go there. It's important for him to know that.

The physician's knowledge around assessment and treatment was important. When Randy was no longer able to cope, he relied on his physician to figure out the problem, "I just couldn't do it anymore … and I had to tell the doctor what was going on … and I talked to the doctor and they figured out what the problem was." Others also commented on the importance of assessment skills, knowledge of schizophrenia and education that they received:

> Elly: … finding a compassionate enough man in the field of psychiatry to, sort of, understand schizophrenia to the point of where he does understand it, and have the knowledge and the resources to, sort of, play around with different medications to find what suits you the best.
>
> Olive: It would be Dr X. for the medication; thank God, he knows his chemicals.
>
> Patty: Well, he's a good clinician, like all my doctors. … All the doctors are, they have value.

Psychiatrists provided an educational component to the relationships. Elly was educated about the neurochemistry of the illness, "You have to understand that what Dr G. told me. I have a chemical imbalance." The clinical assessment and education provided by the physician was part of what they valued in their relationships with their physicians.

An emerging theme in this study related to the value of being held accountable, as already discussed in relation to family, friends, and case managers. In addition, by appreciating their support and knowledge, participants also appreciated honest feedback and gentle confrontation from their physicians. Art explained, "When he needs to give me correction he is not afraid to … challenge me on a belief that I might have." Sam concurred, "He lets me know that I am sick; that I am not normal." The clinical support and accountability was as important as their ability to communicate with their physicians.

12.4.1.1.3 Communication

Communication with the physician relied on the physician's ability to listen to the patient, to be able to communicate honestly, to "read" them a bit and to be non-judgemental. Firstly, people described the ability to listen as important:

> Sam: I know he's listening.
>
> Art: He is gentle, he is honest. He is a good listener.
>
> Patty: I'm grateful for Dr K. in the fact that he listened to me from day one.
>
> Yvette: He listens to me. He is very helpful, he is kind, he's everything, everything. He's one person that I have to say that has really changed my life around.

> Randy: … there is and, you know, that someone actually does care, you know, and listen to what I am saying, and hear what I am saying.

Good communication by their physician also implied that it was safe to be able to communicate their needs honestly. Henry, Art, and Randy spoke of this honesty within their relationship with their physician:

> Henry: … find a doctor that you like and can be honest with and you can communicate with and understands your needs. … We don't know what he thinks, but that is why it is important to have this communication because he is getting information about the illness and we are just trying to lead our lives, so it involves us, but our take on it is probably different, right?
>
> Researcher**:** Is there anything you don't tell your doctor?
> Art: Ah, no, I tell him everything …
>
> Randy: I am pretty open about it, I don't really hide anything from my doctors. I don't lie to my doctors and I tell him what is going on in my head and what is happening and stuff like that. That is the only way that I can get, they can help me, you know, …

Randy and Elly acknowledged that, at times, it was hard to be honest with the doctor and, therefore, appreciated the physician's ability to "read" them:

> Elly: I'd go down to see Dr S. maybe not making eye contact with him, he would have known what was wrong with me right there, he just wouldn't have said anything.
>
> Randy: I don't show it a lot, I don't show that I am scared inside, or that I am hearing voices or this and that whatever. I really keep it to myself, but my doctors know all about it,

Sam recommended that both the patient and the doctor be non-judgemental in their communication with each other: "Don't judge the doctor, the doctor won't judge you." Listening, honesty, reading non-verbal cues and presenting a non-judgemental attitude were important qualities of communication between patient and physician. In tandem with the communication, was the respect given to allow some self-determination. Patients found this respect empowering.

12.4.1.1.4 Empowerment

Participants described their appreciation of being given some control over their treatment and how they found this empowering. Elly spoke of coming to an agreement with her physician after some negotiation regarding her medication:

> … came to an agreement. … He'd ask me how I was doing, and I'd say I'm having this, I'm having this sort of reaction to the medication, I don't like it. And he'd say, Ok, let's try something new, are you willing to try something new? And I'd say, Yes, sure, as long as the side effects aren't weight gain.

Henry spoke of the tension between his physician's knowledge and his rights as a mental health consumer, and of the respect inherent in the give and take of negotiation:

> I think I respect my doctor, if, when he asks certain questions, I respect that he has to ask those because he is the doctor. … He knows where he is coming from, what his training is and what is acceptable. But as the consumer or the mental health person, there are certain things that I have to say and ask too and that should be respected also, and, um, maybe that is something that has to be put on the table from the beginning, right? I have to ask, Is this a voice, or why is it when I bring this up, you always want to medicate me?

Irene brought her concerns to her physician and was empowered to advocate for an increase to her medication, "I did tell him when I was getting a bit agitated, that I wanted a bit more medication." Randy was able to assert himself and be respected in his relationship with his physician, "I talked to Dr X. about that and he wants to take me off of it and I said, No, I won't go off of it, because I don't want to fall into that." Sam felt safe to ask his physician to make a medication adjustment, "I asked Dr Y. if he'd change my medication." Hannah's psychiatrist asked her about going on medication, affording her some choice, "Dr Z. asked me if I was willing to consider going on medication."

Randy's physician downplayed the importance of medication, and, instead, gave him credit for his recovery and better function:

> Dr X. he said, he thinks sometime it is me that is doing that, that I have learned to do that, instead of the medication, that I have learned on my own how to do that.

Sam recommended being assertive with physicians when there is a poor response to medication, "Unless the drugs are helping you, if you're taking them, the doctor prescribes them to you, take them. If you don't feel better in a week or two, don't take it, ask for something else."

While professional support was deemed important, there were other dynamics that had potential to undermine the recovery process. These dynamics were the antithesis of what made the relationships between patient and physician special. Henry spoke of wanting to find another doctor; since his doctor thought he was just a complainer, he did not feel he could be honest with his doctor:

> So you can't tell him about that or … you can't question him about things. And, you know, there was a time when I tried to find another doctor. … He would just say that I was complaining, so I couldn't bring it up …

Henry spoke of a time when his diagnosis was not fully explained to him:

> I really didn't feel (it) was fair, because I didn't understand it, and I was trying to understand it, and should have the right to question the diagnosis, which I never really got.

Peter's physician irked him when he did not honour his spiritual beliefs, "doctors who don't have any spiritual insight whatsoever." Ingrid felt she would not be able to go to another physician when her doctor of 24 years, retires:

> K. (husband) asked me, What are you going to do when Dr Y. retires? And I say, I am not going to anybody … unless I have to.

Physicians who stop listening and honouring the self-determination and beliefs of their patients run the risk of impeding the recovery process. In addition, loss of the

therapeutic relationship through retirement or patient transfer has an impact on recovery.

Respect for the need for self-determination and the willingness to negotiate are important qualities that build client empowerment within the therapeutic relationship. These components neutralize detrimental aspects of the power imbalance between patients and physicians. People in the study appreciated their physician's feedback to hold them accountable.

12.4.1.2 Case Manager

The availability of a case manager was deemed critical by the people who have had, or continue to have, one working with them. Of the nineteen persons who were referred for the study (those deemed to have good insight), fifteen had had case managers, and many, despite good recovery, continue to be supported by a case manager. The evidence derived from the data described six types of support received from case managers that were deemed important to recovery. These supports provided by case managers are discussed further in the next section.

The six types of supports provided by case managers and valued by the participants were: clinical, educational, practical, social, emotional, and vocational support. In addition to the benefits of receiving these supports, it was clear that withdrawal of these supports had negative consequences for people with chronic mental health issues.

12.4.1.2.1 Clinical

Clinical support included a pro-active "checking in" by the case manager, but also contact initiated by the participants when they had concerns. Clinical support was also valued by participants as it held them accountable for their illness management. Carl described how he used his clinical support:

> Just keep in touch with your nurse, at least once every two weeks, eh, keep in touch, no matter how things are going, keep in touch and take an interest.

The family member valued the case manager when she had concerns about her mother:

> I phone and talk to the case worker or Dr X. and give them the heads up. … They phone or pick her up for coffee, or whatever. The case worker … sort of sets things back to ease, or her medication will get upped if she has been sick.

Ingrid, Olive, and Yvette described the clinical support received from their case managers that resulted in being able to see the doctor for medication changes more quickly:

> Ingrid: I told my nurse that I felt like I had electricity shooting through my body and they upped my meds.
>
> Olive: I would say that if not for my nurse, M., she has such a keen eye, she can notice things … definitely so crucial in my development, and my, I would say, escaping schizophrenia. … When I feel that way, I contact M. to make an emergency appointment with Dr X. so I can come in and get diagnosed by him.
>
> Yvette: It is time, Yvette, for you to see him. (I would say), But there is nothing the matter with me, K., why? I just think you should. So then I go, because he knows best. I guess he figures that a little visit with (the doctor) … you know, update things, and maybe, for reassurance for himself.

Ham liked having the comfort of clinical support from his case manager, "because it is like a little psychiatrist on the side". Clinical support by the case manager can include quick assessment of pending relapse and quick access to the physician for

medication assessment. The development of trust and the provision of support allowed case managers to hold their patients accountable. People were able to tolerate confrontation and expectations of accountability from their case managers. Being held accountable and being told the truth were important dynamics between Art and his case manager:

> Accountability is very important. … Because, despite how I was feeling, they always told me the truth.

Olive remembered her case manager's gentle confrontation, "I remember S. telling me years ago, the definition of insanity is doing the same over and over again and expecting a different result." Henry appreciated his case manager playing "hard ball" with him:

> I guess it could have been pretty easy to get mad at him. He liked to play hardball, three strikes and you are out. So, basically, I will be there for you, but with certain rules and one is medication, doctor appointments, stuff like that. … He was really quite good.

The OT believed that being honest and holding people accountable was important:

> … they need to have somebody who is completely in this reality to, to discuss and to bounce things off of, or to get feedback off of, that (I) might not hear otherwise.

Being held accountable is an element of clinical support that persons with the illness valued. Clinical support is an important function of case management and recovery from schizophrenia, as is educational support.

12.4.1.2.2 Educational

People with the illness appreciated the educational support they received from their case manager. Olive received educational support around her health decisions:

> I would say, besides those two, I feel that it was very crucial to a lot of the decisions that I needed to take, and a lot of changes I needed to make to move on from my illness, and to help myself get out of the rut.

The life skills worker saw this educational support as important:

> I think the ones that have more help, … the ones that are getting told more about their illness, … case managers coming in with them … talking …

Hannah felt the educational support she received had been "helping me stay stable, very helpful." Norm appreciated his case manager's humorous approach to education:

> … my, uh, community nurse that I used to have, her name was R. And she used to tell me off, talk to me about people that didn't want to take their medication. … Reframe your thinking, she would say. … Some drug company spent billions of dollars making this medication for you … (laughs).

Learning life skills is an important function of developing independent living and recovery although a new study by Tungpunkom and Nicol (2008) provides some evidence that there is no difference in skills performance by those given life skills instruction and those who receive standard care only. However, people in the study felt that life skills education was important and some had received this from a case manager:

> Carl: In K.'s program, (I) was to take a shower at least three or four times per week. I set it at once a week. I achieved it. And then my next step was a shave, twice a week. I set it at once a week. I achieved it. We set goals. Everyone had a goal to set.
>
> Ham: Well, T. taught me cooking. … People have helped me.
>
> Sam: … had help, had lots of help from N., she was a care worker … got me started in personal behaviour.

Participants valued the life skills and educational support, but they also appreciated practical support.

12.4.1.2.3 Practical

People appreciated the practical support they received in their day-to-day living. Henry described a project where he enlisted practical support from his case manager:

> If I had a project … he would come along and he was like a job coach, almost and he was really quite good.

Randy's case manager helped him with "everyday living sort of thing, help me with skills and stuff like that." Sam's case manager assisted with practical skills such as budgeting his money:

> Yeah, she was coaching me too, as, uh, on a weekly basis, yeah, Mondays and Fridays. She … got me on line and, and said, Hey you got to eat, you got to spend your money on food, you got to spend your money on, on your, uh, rent, utilities. Don't spend it on anything else. To make sure you pay your bills.

Practical support is an element of support highlighted by the people in the study, and within their role, case managers also provided social support.

12.4.1.2.4 Social

People in the study spoke of the types of social support received from their case manager. Henry spoke of his case manager, who met him for coffee, and valued his friendliness:

> I had a case manager. … He'd meet for coffee, and, um, on the weekends he was there, evenings, he was there … K., you know, he is friendly.

Ham enjoyed joking with his case manager and engaging in a game of cards from time to time, "When he comes over, he just plays cards and bullshits; he knows where I stand." Ingrid described her relationship with her case manager, M., as close, "I liked S. a lot, but our relationship was not the same, and I was much better then, so, our relationship was not as close as M. and I were." Case managers provide social support to people in recovery, and through this social relationship, trust is established facilitating emotional support.

12.4.1.2.5 Emotional

Emotionally, people required support and received it from their case manager. Norm's case manager gave him an opportunity to just vent, and this helped him get back on track, "Yeah, just to talk, and, you know, get things on a positive track. And sometimes they start on a negative, and, uh, it takes some work." Yvette appreciated her case manager's listening skills as well, "You know, that someone actually does care, you know, and listen to what I am saying, and hear what I am saying, because before, I don't think that they did." Ingrid appreciated the compassion and empathy provided by her case manager:

> She was very compassionate. She said, It was not your fault, don't blame yourself. … I think I was blaming myself in ways …

Randy appreciated the positive feedback he got from his mental health support team:

> … it is helpful, it is nice to have a pat on the back that you are doing a great job, and that everything is working out, and, you, I am proud of you, and stuff like that. That keeps you going, too.

Sam felt he could talk to his case manager, "She's, she's alright. I'm glad I have her … Miss W., sort of, let me talk the way, what I wanted to say, the words came out, freely, easily, out of myself. I could speak to her." Emotionally, people bonded with their case managers due to their ability to listen to them, and the emotional support delivered. However, case managers also provided valuable vocational support.

12.4.1.2.6 Vocational

Vocational support and encouragement is part of what a case manager can provide to clients. Ingrid spoke of C. who assisted her to volunteer at the Clubhouse. This provided her with enjoyment and extra cash:

> C. took me down to (Clubhouse) and then I worked there for a number of years in a volunteer capacity. I think I made a $100 per month, and I enjoyed that.

Randy spoke of his goals to go to college and his being set up in a provincial agency that assists people with mental health issues to move toward employment goals:

> … like I took these workshops … and I completed them all. And well, that gave me a little bit of confidence. I would like to go to college one day, and, um, you know, be something. It will come, it will come in time.

As discussed, case managers perform six functions in the realm of recovery. These support functions are integral to the role of the case manager and meet the need of the people with schizophrenia to feel interdependent with services and service providers. It also demonstrates that, at times, dependency is apparent (Bonney & Stickley, 2008), but that this dependency is not necessarily a negative state (Perkins, 2003). Strong case management support helps sustain wellness and mitigate relapse. The importance of case management is equal to the importance of physician support. However, the physician's value had different elements for the people in the study.

Case managers and physicians provide aspects of support that is highly valued and appreciated by their clients. Relationships with their case manager and physician support them and facilitate recovery. However, disruption in this alliance through a change in physician or case manager, or an inability to engage in negotiation with their professional supports can impede the recovery process. In addition to the therapeutic alliance, another relationship proved important to their recovery. Their relationship with a diety impacts on their recovery process, and, hence, spirituality is the next chapter's focus.

12.5 Conclusion

Influencing the process of insight development and recovery are four phenomenon of influence. Paradoxically, the *Four Phenomena of Influence* hold the potential to both

facilitate and impede the process. The *Four Phenomena of Influence* are: losses, barriers, relationships, and God. The evidence for the first three influences have been presented here as people grieved their losses, fought the barriers of social construction, expectations, and poverty, and described the importance of their professional relationships. These relationships, primarily professional, were integral to insight development. All three influences have both the potential to impact on and facilitate recovery and are important considerations when developing interventions for people with schizophrenia. The evidence of a fourth phenomenon with a permeating property to the process is the importance of spirituality in the life of the person with schizophrenia. This was a "surprise" finding but also a strong finding of the study, hence deserving of its own chapter. The importance of spirituality is the focus of Chapter Thirteen.

CHAPTER THIRTEEN SPIRITUALITY

> Psychiatrist 1: I am not sure that the question is, Why spirituality is relevant to schizophrenia? as much as, Why is spirituality relevant to human beings?
>
> Positive reframing of unusual mental experiences may enable individuals to find meaning in their symptoms outside of the medical model, for example by attributing a spiritual meaning to their experiences. (Cooke et al., 2007, p. 19)

13.1 Introduction

Spirituality is the fourth influence that permeates all phases of the insight process. Like the other three phenomena described in Chapter Twelve, spirituality both facilitates and impedes recovery. This chapter presents the study findings on God and spirituality.

"God" is the term used to denote the strongest overall finding in the study. Its use throughout this section of the thesis is a reflection of the fact that this was the primary term used by participants to describe their higher being. The word "spirituality" will be used interchangeably with the word "God" by the researcher for the purpose of discussion. God was typically engendered as male by the participants. Out of respect to those Christian people in the study, transcriptions applied capitalization to gender references to God.

Due to the number of times and the number of ways that God was described, it may be that God was their main relationship and their primary source of support. People relied on God; they trusted and had faith in God. God provided them comfort and safety. God was supportive and a partner in life management. Their relationship with God facilitated and moved them toward recovery. A man with schizophrenia in

Wittmann and Keshavan's (2007) study discovered the best known psychological remedy for worry, stress and anxiety was in:

> … entrusting himself to God and Jesus' teachings … the true miracle isn't that … suffering has been completely eliminated, but rather that we change (with God's help) the real root of the suffering and pain: how we view it, how we respond to it. (p. 160)

These findings around the relationship with God are not unique; large numbers of clinicians and researchers report people with schizophrenia use their faith to help them cope (Miller & McCormack, 2006). Over 1200 studies show a positive association between religion and physical and mental health (Koening, McCullough, & Larson, 2001). Bill McPhee, a man with schizophrenia, as noted earlier, and publisher of the Schizophrenia Digest, reported his faith in God helped build self-esteem, confidence, trust, and belonging into his life (McPhee, 2007, p. 56). Therefore, God appears to be significantly relevant to people with schizophrenia.

However, a relationship with God also holds the potential to impede and destroy their recovery. God was a profound source of confusion for people in the study as many of them had had religious delusions during their psychotic state and the memory of a "mystic connection" remained seductive. There is a vulnerability to this seductiveness (Mohr, Brandt, Borras, Gillieron, & Huguelet, 2006). Religion can have both a positive or negative impact on a patient's life. Without a sense of balancing the religiosity or intensity of the spirituality, the negative impact may be overwhelming. People struggled with knowing or recognizing whether their relationship with God was within normal limits or whether they had crossed a line into the world of psychosis. Fear of blurring these boundaries provoked them to develop management strategies to handle their real concerns of engulfment into the world of religious

delusion. Vigilance was required to ensure they balanced healthy spirituality against religious delusion. These concepts on spirituality are the focus of this chapter.

13.2 God

The analysis of the data relating to God revealed the importance of this aspect of participants' lives. They spoke about their reliance on God, finding comfort and safety in their religious beliefs and practices, maintaining a relationship with God, ensuring their spiritual source of support remained within healthy limits that balanced their vulnerability to psychosis.

13.2.1 Relying on God

People relied on God for support:

> LSW: … some individuals really do need that, spirituality is not just about God and it is about their inner strength and what they utilize for support**.**
>
> Olive: I accept the fact that I need medication and I need cognitive therapy and things like that, but I also believe that my God has helped me. … I am pretty much alone … I know. … He's helped me.
>
> Yvette: I just believe He is there for me all the time, at any time and all the time.
>
> Elly: Mmmm, maybe because it's a miracle that I'm here alive today. So I do, I do believe in a greater power, or I do believe that there is, um, more, more than we see out there. Um, I do believe that. … I'm able to express my own, my own definition of what my own God is. So, finding God within myself and seeing it in every other human being that is alive, I think that is an understanding of God.
>
> Ingrid: I really do believe in God. I don't even know if I would call it God, but God helped me get through it.
>
> Art: … faith, um, perseverance … Love, for others, for God, for myself. There is always one piece in there that helps. It is not coming from me but coming from someone else. When I am along praying, it comes from God.
>
> Carl: … every morning I wake up and I say, Thank you, Jesus, for allowing me another day. Thank you for the food, thank you for what I have. By doing that he makes sure you have plenty, eh, long as you pray, once in the morning. … Ya, if you pray to Jesus and give thanks for what you have you will have

> plenty. So cherish, say thank you for the life you live, for the air we breathe, all the things that are important, cherish.

When asked what her greatest support through her recovery was, Olive stated, "My God, ya, definitely, my God." Norm admitted he relied more on his faith when he is sick, " Um, when I am sick, I tend to rely more on my faith than when things are going more normal … yeah, spirituality is important to me and, uh, it's probably more important to me when I don't have it.

The OT in the study described how one of her clients with the illness had relied on God to assist him to differentiate between delusion and reality:

> OT: He has schizophrenia and he knows it, and he knows when these episodes occur that they are a psychosis. And so I asked him how did he learn to discern that, and he said, In the beginning, I thought it was all real, (but) … He asked God to help him figure out what is real and what isn't real and he believes that is how it happened. So that was his answer to that.

People had faith and trust in God; He was taking care of them; they were in His hands:

> Henry: I just have to go by the grace of God that my mind kind of stays in control, eh?
>
> Olive: and because of my religious beliefs we believe in a wonderful future.
>
> Peter: I'm not in control, only God is in control for me … because God has more compassion, wisdom and understanding than me, right? What he puts me through at the same time … Why am I going through this? … You just have to surrender it before God.

This evidence from the study demonstrates the enduring presence of a being that can be relied upon, even, and especially, during difficult times and, perhaps, demonstrates a counter-obligation to give thanks and to have faith and trust in that higher power to provide what they need. God provided them with comfort and safety in exchange for this faith and trust.

13.2.2 Comfort/Safety

People derived comfort and safety from knowing that God was in charge and watching over them and they sought God's house and His people for additional comfort:

> Randy: All I do when things like that happen, and what the voices tell me, I just pray to God it doesn't happen, and nine times out of ten it doesn't happen. … God, I believe in God that's helped …
>
> Art: I get comfort out of prayer, and I believe that God loves me and doesn't want me to suffer.
>
> Peter: I look to God when things get rough and it is actually a spiritual experience.

God's house was a source of comfort and safety:

> Art: … when I sit in a church, just by myself, especially the Catholic Church, you can smell the candles and the stained glass and I find it peaceful. When I first was diagnosed with schizophrenia at sixteen, they had a chapel in the psych ward and I found that when I went in there, I felt safe.
>
> Carol: I go to the chapel sometimes at the mission for support, but I am not a religious person.
>
> Henry: I find the church is kind of good for me.
>
> Irene: Well I kind of feel safe with church, too, eh? … When I go to church when I am sick, at least I feel safe and somebody can help me. … I have peace going to church, I really do, and it is a quiet time, and come home, and if I don't go to church on Sunday, there is something missing.

Randy summed up this theme of comfort and safety:

> I believe, I totally believe in God. Every morning I pray to God, that I turn my life and my will over to Him every day, and he guides me through my day and you know, there is no problems. And I do really believe in God. I don't know much about religion, but, ah, I know there is a God out there. There is, that's what I think anyway, and that is what keeps me alive.

Philips and Stein (2007) report in their study that persons coping with serious mental illness, "can and do utilize religious coping strategies that are considered healthy" (p. 537) and are positively correlated with perceptions of personal growth. Relying on

God was an important theme that seemed to offer people in the study emotional comfort and safety. However, this was not just a passive action of receiving God's gifts, but an active action that placed counter-obligations on the participants to demonstrate trust and faith in God and a sense of being in partnership with God to achieve this comfort.

13.2.3 Partnership

While people relied on God, they acknowledged that they had to do the "footsteps" or their part of the bargain as well. They partnered with God toward wellness, and again, there is a theme of counter-obligation in the relationship:

> Hannah: I don't understand it, but like, it is there. and it is up to me to do the best I can with what I have to work with and the good Lord make up the difference (laughs) … because if I want God to answer my prayers, I have to be honest with my fellow man, my sister, my brother. This is what the Bible says you do, you don't lie, because the Lord doesn't like that.
>
> Yvette: I just believe that the good Lord has given me that gift of knowledge, um, of respecting myself, of, and then listening, it is hard to listen to your family tell you.
>
> Zack: No, um, God helps those who help themselves, so I helped myself.
>
> Carl: … if you pray to Jesus and give thanks for what you have, you will have plenty.
>
> Henry: … you kind of go on line with a higher power, you kind of doing your bit, maybe luck will go your way.
>
> Sam: … I knew then that I had to respect religion, 'cause it's sort of a good thing.
>
> Olive: I needed to make to move on from my illness and to help myself get out of the rut, so ya, Dr X., my case manager, and me, and God (laughs).

As participants saw it, in partnering with God, they recognized they were accountable to Him for their part in their recovery and did what was within their control to receive God's support. God was a source of support and comfort, and the counter-obligation

was faith, trust, and being responsible for their part of the bargain. Reciprocity was present in their relationship. While they trusted and partnered with God in their recovery, vigilance was required to not go "overboard" with religion as they ran a risk of re-engulfment in psychosis. Below, people speak of this risk of engulfment into religious delusions and how they managed it.

13.2.4 Balancing Religion

> Psychiatrist 2: There is something mysterious in religion and, unfortunately, it often draws people with psychotic disorders because of the mysteriousness. … They are drawn toward religion, because they are trying to find answers to questions that they have noticed so far that other people cannot answer. So, I think that, unfortunately, it is a double-edged sword, some people with schizophrenia can use religion as an anchor and some people lose and often get entrapped by religion and it is actually part of the trauma.

God was a conundrum for the study participants; a dramatic source of ambivalence. On the one hand, they relied on God for comfort and safety, for strength and partnership, yet on the other hand, so many had been very ill with religious delusions. These delusions were seductive through their mystical significance and the meanings people attributed to them. People with insight had the ability to recognize that "too much religion" was not healthy for them, and that it had the propensity to cross them over into madness. They worked hard at placing some limits on their religiosity. A psychiatrist and the OT discuss this conundrum:

> Psychiatrist 2: I don't think that there is single client that doesn't eventually bring up religion, either as part of their delusional network or that they want to get a sense of what I think of that aspect of religion. … Someone bigger than I will help me fight this and when they really feel that they are losing, then the ally becomes an enemy…
>
> OT: … when I used to work in the hospital … people were … floridly in the throes of psychosis. The Bible was the big reading material on the ward and some people really needed to have their nurse's help in putting limits on how much and how often they spent reading the Bible, because it was, very often, a trigger for … delusions or more ideas of reference or various things. … Once people's psychosis starts to subside, then they can get back to … reading the

> Bible or doing their church services that they would normally do because they seek comfort in them more than when they are unwell …

Sam, Ingrid, and Peter admitted their vulnerability to religious delusions:

> Sam: And I was overwhelmed, by my spirituality of God … I have a spiritual, uh, way of thinking, way of dealing with things.
>
> Ingrid: I couldn't sleep and I was lying in bed and I felt, and I've heard that this has happened to other people too, like a bolt of electricity went through my body, and then it was like I heard a voice, I baptize you, Ingrid. And of course, being with Pentecostal people, I thought, Wow, I've got the baptism of the Holy Spirit.
>
> Peter: … it is more like a spiritual thing. I feel like the Native view of hallucinations, they call it visions … ya, it is part of my spirituality.

While they were drawn to the spiritual and the powerful memories of their mystical psychotic experiences, people in the study recognized that they were at risk of being completely drawn in and engulfed by their psychosis. Setting limits ensured this did not happen. The difficulty of managing their spirituality with this vulnerability to delusions was explained:

> Psychiatrist 1: I think immersing yourself in anything is a risk, even if you don't have a psychotic disorder. … There will be some things that will be easier to keep in balance, so, for example, if you have an eating disorder, over-exercising is going to be a vulnerability for you. … So, there are going to be some things for all of us that are easier to manage and harder to manage, depending on who you are and the milieu you are in and all that sort of thing. We all have strengths and vulnerabilities.

Some participants described how they managed or maintained balance to this vulnerability:

> Art: I used to get delusional when I read the Bible, but what I started doing … I bought Billy Graham daily devotional where it is just one verse and it explains it, and I find if I do it just like that, it is ok. But if I read the Bible too much, I get delusional. … I don't hang around with Christians that talk about Satan, some of them are a little bit fascinated by that and I am not.
>
> Irene: … like my doctor he'll (laughs) ask me, Are you getting religious and going to church too much? Right away … if I say … Jesus is going to heal me, well it is, right then and there, he knows that I am sick. … I think he realizes that I don't go overboard any more … so it doesn't bother him that I go to church every Sunday.

Ingrid and Sarah continued to struggle to maintain this balance:

> Ingrid: It is confusing … I should just give up on religion, because it just frustrates me. … So, I don't know, I sometimes think that I will never come to terms with my religion.
>
> Sarah: I used to pray a lot at one time, and I prayed and prayed for me, and then I stopped praying, and I just prayed all day long, and then I stopped praying, and now everybody is getting shifted. … I pray to make them go away … they help me fine in the long run.

A spiritual continuum exists from a dominant and positive support to the dominant and negative danger of religious delusions and psychosis. People needed to limit their spirituality in order to avoid psychotic engulfment. While religious delusions were frequent for patients experiencing their first episode of psychosis, these receded with treatment. Despite treatment, "faith remained an issue throughout treatment; sometimes related to delusions, but at other times involved in existential crises, or proved a helpful means of coping and re-establishing a sense of self" (Miller & McCormack, 2006, p. 37). Bhavsar and Bhugra (2008) argue for the reassessment of the importance of religious delusions based on new ethnographic and clinical evidence.

Globally, all cultures appear to have some religious foundations (Swatos, 1998). Spirituality and culture are an important part of the human experience (Tisdell & Tolliver, 2001). The dilemma for people with a psychotic disorder is to differentiate between psychosis and a religious/spiritual experience. This dilemma also exists for psychiatrists in making the distinction between the two for diagnostic purposes. Barnhouse (1986) provides specific criteria for differentiating psychosis from the voices and visions relating to mystical experiences. He states that psychotic responses are highly idiosyncratic, usually having to do with the self, or another being involved, but in a paranoid way. Normal responses are in the direction of "healthier self

understanding, better relations with others or constructive action of some sort" (p. 102). May (1992) reports that in the face of mental illness, normal responses to spirituality include a sense of humour, good functioning, and the ability to display compassion.

Traditionally, clinicians focused on the psychological dimensions of practice and left the spiritual dimensions to clergy and other religious personnel. However, Sperry, (2001) states:

> (The) reality is that the psychological and spiritual dimensions overlap considerably. Today, many clients are insisting that clinicians deal with both the spiritual and the psychological dimensions. Accordingly, the challenge for contemporary clinicians is to become sufficiently conversant with religious and spiritual dynamics to meet client needs and expectation. (p. xi)

Given the significant evidence that spirituality has importance for people with schizophrenia and given their confusion in differentiating what is spirituality versus psychosis, clinicians need training in order to assist their clients in this discernment. Additionally, the evidence in this study backs up the assertion by Dr Andre Gagnon, (as cited in Hodges, 2007) that people with chronic illnesses like schizophrenia who are "engaged in some kind of religious activity or inclined toward spirituality are able to tolerate more of the burden of their disease." (p. 32). Gagnon believes religion helps people to find a community for a sense of belonging, but also to find or acquire beliefs that "keep hope alive when you face difficulties" (p. 32). Young and Ensing (1999) also find a connection between spirituality and hope. Physicians and mental health personnel are challenged to engage in discussion about religion and spirituality and to "inquire with the patients about their beliefs and their expectations and encourage them to look at that and use that moment to deepen their approach or their search for meaning" (Hodges, 2007, p. 32). Personal faith cannot be ignored by

mental health professionals (Miller & McCormack, 2006). The findings of this study support such comments and echo the views of clinicians and researchers who report people with schizophrenia use their faith to help them cope (Miller & McCormack, 2006).

The findings from this study that God is largely a source of support for people with schizophrenia is in contrast to the writings of the fathers of psychiatry. Sigmund Freud wrote, "Religion would thus be the universal obsessional neurosis of humanity" (as cited in Koening, 1997, p. 23). Albert Ellis, founder of the Rational Emotive Therapy Foundation wrote, "Devout, orthodox or dogmatic religion (or what might be called religiosity) is significantly correlated with emotional disturbance" (as cited in Koening, 1997, p. 25). Dr Wendel Watters, a Canadian professor of psychiatry, published a book in 1992, which included the following passage:

> Despite the so-called comfort of the Christian message, Christian doctrine and teachings, deeply ingrained as they are in Western society, are incompatible with the development and maintenance of sound health. … Simply put, Christian indoctrination is a form of mental and emotional abuse. (as cited in Koening, 1997, p. 27)

Watters (2007) further questions the importance of spirituality to those with the illness, "Self reporting of psychiatric illness on the part of the believer is notoriously suspect" (p. 406) and challenges his colleagues, "it is a bit strange to see psychiatrist still trying to find something potentially healing in this destructive delusion — although addiction to this delusion might possibly protect one from becoming addicted to a pharmacologic substance" (p. 406). The beliefs of the early writers of psychiatry continue in some psychiatric professionals today yet are in contrast to the voices put forth in the study. This may be a reflection, in part, of the medical model that is largely based on quantitative research methodology. Baetz, Bowen, Jones, and

Koru-Sengul, (2007) suggest to Watters that his beliefs on the issue of spirituality might interfere with his ability to appreciate empirical evidence available and forthcoming on the subject of spirituality.

The Adverse Childhood Experiences Study (ACE) is an ongoing longitudinal study of over 17,000 people who suffered adverse childhood experiences (Felitti et al., 1998). Dr Feletti (2008, January) related that people in the study told him that often, when nobody else cared, they held onto the belief that "Jesus" was there for them. Feletti believes the belief in a higher power was a protective factor or a form of resilience to poor outcomes of adverse childhood experiences. Deep ideological divisions in religion are expected, but evidence from this study demonstrates that spirituality cannot be ignored as a source of support to people with schizophrenia.

Participants reported that God is a source of strength and support for them during their recovery process, yet acknowledge that unless they balanced spirituality with their delusional beliefs spirituality also had the potential to impede their recovery.

13.3 Conclusion

Schizophrenia comes at great cost. Over their lifetime, people with the illness grieve the loss of their potentiality and endure the barriers of stigmatization to the degree that they have "internalized stigma" (Ritsner & Phelan, 2004). This internalization is a construct reflecting the degree to which a person has internalized socially endorsed stigmatizing beliefs about mentally ill people and their behaviours. When internalized, they negatively affect the process of recovery, when externalized, they facilitate the process. These findings must be considered as a practice issue for social workers

working with people with schizophrenia. Practice may need to include honouring their beliefs, utilizing their spirituality as a source of support for recovery, but also may demand assisting people with the illness to balance spirituality and delusion. The *Four Phenomena of Influence* have potential to both facilitate and impede the recovery process and include losses, barriers, relationships, and spirituality.

The following chapter is a narrative analysis of the overall findings. It provides an additional layer of analysis to the findings to determine if similarities or parallels exist to the grounded theory analysis. This layering of analysis can help build data reliability and aid greater understanding.

CHAPTER FOURTEEN NARRATIVE ANALYSIS

> Individuals use storytelling to give meaning to their experience, negotiate the meaning of the events, make choices in the social sphere and build up an identity. It is through these stories that they move around successfully in a complex world, or fail in this task, achieve their objectives or fail to do so, consolidate their ties of belongingness, and manage their subjective suffering and relational problems. (Dimaggio, 2006, p. 103)

> … telling one's narrative, uncovering the strengths and assets embedded within it, untangling and externalizing the negative dominant discourses — results in a transformative re-authoring of one's experience, triggering new meanings and personal and political growth. (Onken et al., 2007, p. 13)

14.1 Introduction

Chapter Fourteen articulates a narrative analysis that has been employed alongside the grounded theory analysis. The narrative analysis examines the cycles and patterns of the illness and discusses the events that turn the person from illness to recovery. As well, it provides examples of messages and warnings people in the study deliver to their peers. Finally, narrative analysis reveals the role that personality may play in the insight development process.

Narratives are important units of discourse. They allow for the construction and expression of meaning; they help us to make sense of our experience (Burnette, 1994). Narratives allow research participants to re-author their experiences and enable them to shift from hopelessness to a life story that engenders the possibility of change (Ridgway, 2001; Roe & Chopra, 2003).

Narrative analysis research is appropriate for the study of insight development in schizophrenia as both researchers and practitioners need to understand what makes sense for persons with the illness, and with that knowledge, they can construct

meaningful and functional interventions that lead to recovery. Generally, the perspectives of mental health clients are included in "only the most superficial and patronizing manner" (Gill, 2008, p. 183), but a narrative analysis takes great interest in these perspectives. Narrative analysis correlates well with understanding the effects illness may have upon a person and their support people (Overcash, 2004; Roe & Kravetz, 2003). Narrative analysis builds a story from the words of the participants and their understanding of their personal experience.

A narrative contains three dimensions: the temporal dimension (patterns of happenings), the social dimension (someone is telling something to someone), and the meaning (a plot giving the story a point and a unity) (Kvale, 1996, p. 200). Narratives in this study contained these dimensions. In the temporal dimension, there was a sequential, chronological order to the stories told by the participants. The telling of the story, and conveying of its meaning to the researcher took place in the social dimension. Finally, the researcher interpreted the meaning and importance of each narrative by listening, examining the raw data, and interpreting it "whilst being faithful to the original stories" (Holloway & Freshwater, 2007, p. 15). Many of the narratives were rich, when the participants were able to "hold the floor for lengthy turns and sometimes organize replies into stories" (Riessman, 1994, p. 69). However, other narratives had elements of barrenness, impoverishment, and disorganization (Lysaker & Lysaker, 2002). These stories had to be excluded, not because they lacked merit, but due to fragmentation requiring significant reorganization (Dimaggio, 2006).

This chapter on narrative analysis will be written from a first person perspective, as locating myself in the research is necessary since "the construction of any work

always bears the mark of the person who created it" (Riessman, 1994, p. xv). I was not merely a "fly on the wall" (Baptiste, 2001, p. 15), nor an observer in the research. Rather, my semi-structured research questions influenced the data and, in turn, the interpretations placed upon the data. The "creative rendering of the subject's life" (Daiute & Lightfoot, 2004, p. 3) also influenced the narratives as they were "from my eyes, with my personality, biases, history and sensibility" (Riessman, 1994, p. 135).

> Sometimes the truths we see in personal narratives jar us from our complacent security as interpreters "outside" the story and make us aware that our own place in the world plays a part of our interpretation and shapes the meaning we derive from them. (Riessman, 1994, p. 211)

The interactional process of the interview provided an opportunity for reflexive discourse. The semi-structured, open-ended questions provoked memories of the participants' experiences surrounding their illness. Remembering is a subjective event; a bringing to consciousness a state, event or condition that is real in the eyes of the participants (Ochs & Capps, 2002, p. 127). Derived from this discourse is the research data. The interactional design provoked memories and musings conveyed in the personal stories, highlighted the psychosocial context, and revealed the significant and impacting life events on the person. The value of grounded theory methodology is that it fractures all these data, these memories, revealing all parts of the narratives, and this forces the researcher to evaluate what each part means. This valuable coding method shapes the theoretical structures of the research findings, but in the process, the "whole person" is fractured; hence, it is easy to neglect and lose sight of their story. Micro fracturing of the data can also lead the researcher to miss macro themes in the data. Therefore, a narrative analysis of the findings "glues" the puzzle pieces together to reveal the full dimensions of the picture. For instance, the colour red in a puzzle piece is only about colour and shape. The colour and shapes reveal the red

wagon only once the puzzle is completed. Seeing the picture as a whole makes the objects visible.

Over the course of the research, it became clear that the participants were motivated to take part in the research for several reasons. Participants advised me that one of their reasons for taking part in the study was to help me to achieve my PhD. Altruistically, they revealed a willingness to participate in a process that could advance research on understanding of schizophrenia. This willingness was beyond any of their personal goals. However, the narrative analysis uncovered deeper, more intense, subconscious, and very personal motivation in that classical "re-authoring" (Ridgway, 2001; Roe & Chopra, 2003) took place, not so much for their own lives, but for the lives of others who were newly diagnosed with schizophrenia. Re-authoring gave participants hope that through their stories, they might give hope to and facilitate earlier recovery for others. Perhaps they found in this re-authoring a means by which to change the past, to re-live, vicariously, through someone who heard their message earlier in the journey than they had. This was unexpected, yet refreshing, and, somehow, noble. Narrating their stories to the researcher provided them this opportunity.

Replete with vignettes, the narratives convey important information to this research on insight development in schizophrenia. It was difficult to select focal points from amongst the many themes and devices (ways) participants used to tell their stories. I had to ask myself, What are they telling me? What do they want me to convey? What is the essence of their stories? What is the central theme? In keeping with these questions, it was clear that the narratives of primary importance were the stories told

around the cycles and patterns of the illness prior to recovery, the turning point, and what sustained their recovery. Participants beseeched me, as the researcher, to be explicit about the warnings and advice they wanted to convey to others with schizophrenia. The participants also prevailed upon me to pass information to mental health professionals; they wanted them to be advised to keep doing what works (for example, repeating the message of the importance of taking medication). I noticed that people, during the interviews, had moved from first person accounts of what had happened, to addressing and engaging a second person, me, as the researcher, in a type of transference. This transference is different from the transference of psychiatry, but rather, it was where I symbolized the targeted audience of their peers with the illness. For example, "If *you* are not sick anymore, it is because *you* have been on medication for a while." This transference is the heuristic device that tells the stories.

In addition, participants used metaphorical devices, such as similes and imagery, in their stories to warn peers with the illness of the consequences of not taking treatment seriously. These devices include images of doors that swing and revolve, electrical imagery, rock imagery, and physical body imagery to describe aspects of their particular turning points. The actual quotations within the findings have been well documented in Chapters Eight, Nine, Ten, Eleven, Twelve, and Thirteen and will not be repeated here except for occasional illustration.

14.2 Cycles and Patterns

Hannah used a simile of the revolving door to explain the cycles and relapses of the illness. The revolving door of mental illness; what is that? Metaphorically, the door symbolized the cycles in the *Period of Chaos*. This abstract door is a revolving door

that refers to the doors of the hospital, pharmacy, workplace, prison, and home and to the revolving cycles of substance abuse. The door also refers to the potential for re-occurring brain damage, and the subsequent cognitive deficits, as well as the re-occurring belief that there is nothing wrong.

Most obviously, the hospital has a revolving door. Hospitalization and re-hospitalization are veritable signs of relapse (Thieda et al., 2003). Conversely, hospitalization and discharge are signs of recovery. Admission to hospital represents acute illness and the belief that there is danger to self or others. However, discharge from hospital is generally indicative that the acuteness has lessened and that the person may be on the path of recovery, signifying compliance with the treatment plan. Subsequent re-hospitalization may be a sign of not adhering to a treatment plan. Re-hospitalization revolves the door.

Pharmaceutical treatment is a revolving door. Medication adherence leads to recovery, but medication nonadherence leads to relapse (Agarwal et al., 1998). Medication non-adherence, skipping medication, deciding they did not need their medications, and/or did not want to take them all, contributed to encounters with the revolving door as they provoke relapse. The respondents, in their stories, asked their peers with the illness to notice this: “When you are not sick, notice you are on medication and when you are sick, you need to notice you have stopped taking medication.” They provided blunt advice to their peers with the illness: “There is no cure for schizophrenia.” “It is a life-long illness.” “There are only pharmaceutical controls.” “You will get sick if you stop taking medication.”

The workplace/volunteer work/school have revolving doors where participants entered and exited work/school, dependent upon their medication adherence and the impact of stress. Stress inevitably plays a role in the life of a person with the illness who is also trying to work (Krupa, 2004). Participants spoke at length about the fine balance they maintained between expectations, obligations, activities, and solitary "down-time". Doing too much broke the protective bubble that medication provided and rendered the medication ineffective. Many learned the hard way that having high personal expectations around work/school had a serious negative impact on their functioning before they learned how to get the door to stop its revolutions. They had to learn to find that fine balance.

Entry and exit from prison involved the revolving door phenomenon. People recognized that their voices commanding homicide or aggression, and the threat of acting upon these, threatened the safety of others (Swift, 2000). They seemed to appreciate these behaviours were not and should not be tolerated by society as they were dangerous. Conversely, they ran the risk of harm by others when they responded to the voices and acted "nasty" or like a "weirdo". The consequences of their actions created the potential for the prison door to swing.

Home also had a revolving door. Medication non-compliance can increase the expressed emotion (Butzlaff & Hooley, 1998; Kavanagh, 1992): worry, angst, and ambivalence in the family. Generally, families want the best for their children or siblings, but family members often do not understand, or they succumb to the stress imposed by mental illness. There is a suspicion the person is not trying, and the family is worried about their future. When the person goes off medication, it illicits

fear in the family: Will he ever be normal? Will she go to jail? Will I have to care for him forever? Why doesn't she work? How can we keep him on medication? Families are largely responsible for the caregiving (Xiong et al., 1994), but the family's fear and exhaustion can sometimes lead to the person with the illness no longer being welcomed in the home. Family relationships improve when the person is on medication, but when the person is off medication there is a "spoiling of trust" and often a removal or withdrawal of support from family who feel they need to create distance to protect themselves from disappointment, obligation, and hurt.

Substance abuse is like a door that revolves in a "vicious cycle" that leads to suicidal thoughts, lack of funds for basic needs, poor judgement, provocation of psychosis, poor hygiene, and apathy. Inevitably, substance abuse leads to relapse and re-hospitalization (Heinrichs, 2003). Participants advised others that in order to avoid the revolving door, they should take control, as Elly said, "by taking yourself away from that path" of substance abuse. Abusing substances created a dangerously revolving door.

A revolving door is further present in participants' relationship with medication adherence. Hannah had awareness that going off medication assaulted her brain, causing a risk of brain damage and further cognitive deficits; a slippery slope of further functional decline (Seedat, Fritelli, Oosthuizen, Emsley, & Stein, 2007). Attitude played a role in this revolving door. People denied the illness and refused treatment (Forsyth, 2002). People refused medication, did not want medication, and, therefore, had to learn the hard way that this door led to relapse.

Participants expressed hope that others with the illness would hear their stories and heed their advice, and, hence, would not subject themselves to the cycles. But they also recognize that despite their own initial failures, they were able to re-hinge the revolving door to swing just one way — to recovery. Elly's description of "being stuck in a cycle" was vivid. One can imagine a person caught in the spokes of a cycle or a rat on a treadmill, going nowhere, but round and round. Henry used the metaphors of heartburn or fire to describe the cycles of "learning the hard way", "How many times you can get a touch of heartburn or if it hurts every time you touch it, eventually you just stop." He also used the metaphor of "two bulls going horn to horn". He was the bull of resistance against his physician's bull of forced treatment. Emotional pain forced other choices. Resilience to endure these dizzying, frustrating cycles and patterns engendered hope and readiness to begin recovery work. These cycles were the lessons learned, and all that was required was a significant event to begin to apply these lessons.

14.3 The Turning Point

From the analysis of the narratives, there appear to be three factors in the turning point between the cycles and patterns of illness and relapse and wellness. These are: an event, the construction or meaning making of the event, and hearing a connective message that made sense.

14.3.1 The Event

Participants told stories of events and invariably used imagery to describe the impact and significance of the event. Carol used an electrical metaphor to describe the consequences of her event, "that event kind of gave me a jolt". Carol used this

metaphor to describe how the jolt pushed her into recovery, as ranchers use an electric prod to direct cows into a chute or pasture. Randy used his eyes as a metaphor to describe his event. His event was an "eye-opener". The imagery of "eye opening" conveys the notion that in the chaos, he was blind, but the event provoked vision and clarity. Many referred to hitting bottom: "rock bottom", "didn't want to be on the bottom anymore", "hit bottom". These events provoked a turning point where the participants decided they must take responsibility and control over their illness.

Chapter Eight provides ample evidence of the turning point events and the danger they presented; no repetition is necessary here. The participants used the researcher as a conduit to channel messages to others with the illness and these messages are the focus of this section. Heuristic devices deliver these messages.

The *Oxford English Dictionary* (2004, p. 1107) defines a point as "a particular spot, place or moment, on the verge or brink of ". In this study, the concept of a "point" was used to describe the spot that delineated the brink of recovery, the moment of change, and the spot where chaos is left behind, "I was at that point", "once you reach that point", "having a point", "I guess it was a turning point". Participants recognized a definite point at which they made a decision to change. Metaphor and imagery illustrated the word "point", but rather than an external point or marker, the point was an internal cognitive shift (construction).

14.3.2 The Construction

Metaphors described this turning point and explicated the cognitive construction people made of the event. For example, “You just get fed up.” Here, Olive used a food metaphor to describe her turning point, her internal cognitive shift, “Once a person has eaten enough, they stop eating”. Metaphorically, this tells the story of a person who, once they have had enough of the chaos, they stop. Sarah reported there was a point where she “turned the corner”. Metaphorically, this gives the image of a person walking down a road and once turning the corner, seeing a new, fresh landscape. To Carol, however, the landscape looked different because of the cognitive shift in her thinking. Carol said, “I made a decision.” Olive said she had “had enough”. Here again, the words “decision” and “enough” were used to describe a point of change, an internal cognitive shift. Participants used heuristic devices of literature and language to express action and to describe their turning point. The inevitability of a serious event is the respondents’ message in the next section. There is also discourse and a divergence of opinion as to whether one can learn from the mistakes of others.

14.3.2.1 Narrating the Construction

“Eventually,” the participants realized, something was going to happen when a person was off their medication. Randy said it was just a “matter of time”. Carl said, “Eventually, you will hurt someone or someone will hurt you.” Ending up injured or dead was another distinct possibility. “Hitting rock bottom” was also inevitable. Eventually, an event did occur creating a point where participants made a change, or made a decision. This decision was that it was too dangerous to continue in the same way. Change must happen. The decision and meaning making (construction) of the

event became the point where the linkage between illness and management of the illness occurred. The point of realization and elaborated narration of impact combined to break the ambivalence and provide the motivator. Three examples of linkage between illness and management were provided. Carol said, “once your reach that point, you do whatever it takes to keep yourself safe.” Her quotation can be broken down to illustrate the linkage between illness and management; “once your reach that point” (linkage/danger), “you do whatever it takes” (management), and “keep yourself safe” (from illness). Participants narrated the event and described the turning point and the aftermath of their decisions.

Henry said, “having a point in my life” (illness), “where I did not feel safe” (linkage/danger), “because of being off medication” (management).

Olive said, “I was so depressed that all I did was sleep” (illness), “I just wanted to sleep my life away” (linkage/danger), “and I thought, NOO … I can’t let this happen” (management).

The linkage is provided by the recognition of danger, and this couples two concepts that were previously disconnected: illness, to illness management. The link is a decision based on dangerous meaning making which allows recognition of the illness to become associated with management of the illness. The findings in Chapter Eight provided evidence of the meaning making of the events, while these narrative stories of resistance and struggle, and denying the illness, give some indication of how very dangerous the participants perceived the event to be and how necessary it then was for them to make change. The meaning making of dangerousness leading to the

recognition of the illness says, “I am not normal”, “I am mentally ill”, “I am different”, “other”. It is an invidious decision that separates people from their potentiality, and their hopes and dreams for the future. However painful, this is not as painful as the risk of another event. There is a greater discomfort in not changing than in changing. Recognition of their illness and of the danger it presents finally occurs and is linked to the acknowledgement that they must actively manage this real illness.

14.3.3 Messages (Hearing a Connection)

Once the process of change is narrated, these stories now become messages to others. From the turning point in their storytelling, participants now prevailed upon me, as the researcher, to carry their messages to mental health professionals, peers, and families of the importance of repeating messages that provoked treatment adherence. Their narratives story events that create linkages between illness and management of symptoms, now were in conjunction with messages from mental health professionals that made sense to them. While they could not always hear these messages, the dangerous event created receptivity to these messages and a willingness to integrate them into the management of their illness. They wanted to impress upon professionals that despite the fact that often it may appear these messages are not heard, they are in fact heard at some level; seeds are planted. The messages, if repeated, will eventually be available for recall, and at that time, meaning making of the message will occur.

Carol described how a message from her nurse regarding medication fidelity “eventually … finally sunk in”. Her statement creates imagery of an osmotic process where liquid or gas moves across a semi-permeable barrier and goes from a high concentration to a low concentration. The high concentration of messages from

mental health professionals, together with the high concentration of the meaning making around dangerousness in her mind, finally moved across her cognitive membrane and diffused into the low concentration of understanding within her. Despite numerous professionals repeating the same message about medication, Carol admitted she was "finally ready to hear it". She was also then able to hear that her dopamine levels were high and that she had a chemical imbalance. It now made "sense". Olive also heard a message that made sense of her cycles or relapses, "The definition of insanity is doing the same thing over and over again and expecting a different result."

Hannah's case manager drew the connection for her between her de-compensation and her attitude toward her mother, and this "clicked" for her. Henry's physician pointed out his increased organization and this had meaning for him. Professionals noticed and remarked on the improvement of Norm's coherence and Peter's quieting voices, and these messages were received. That the use of medication formed a bubble around him, was a message that Art heard following his turning point. When motivated receptivity was present, it was possible to compare management to other chronic illnesses, like diabetes or hypertension. The following messages from participants provide mental health workers with clear guidelines for practice:

> Randy: It is just being stressed over and over again by doctors and counsellors.
>
> Sam: … you have to be told over and over and over again before you realize.
>
> Art: I needed to hear that over and over again.
>
> Carl: … people have to keep repeating that to you until it finally sinks in; that you've got to take your medication every day.

Who was Carl referring to when he said people? People are parents, siblings, case manager, doctor, hospital, and community mental health workers. All need to

reinforce these messages to people with schizophrenia, and, in fact, it may well be a professional obligation:

> Carl: You have to let them know what will happen to them in the future. They got to know ahead of time, so, somehow, they can change their life. They got to know ahead of time what they are up against.

The importance of hearing the message repeatedly was stressed by most of the participants: "told me the same thing", "keep repeating that until it sinks in", "you gotta take your medication every day", "if you miss, you will hear voices", "take your medication", "you to keep taking them", "told me the same thing", "just being stressed over and over again", "she used to tell me", "many people said that to me", "told over and over", "let them know ahead of time what will happen to them", and "let them know about it". Repetition of the message was considered crucial. Hearing the message, together with the event and the construction of meaning making of dangerousness, was the third aspect of the *Turning Point,* and, therefore, gives some credence to the theory of the *Trinity of Crisis.* The triangulation between narrative analysis and grounded theory analysis may provide additional support for the *Theory of Dangerousness.*

14.4 Intercessions

Participants also provided mental health professionals with intercessions. If a patient returns to hospital for the second time, this should raise a red flag for mental health professionals. This is a warning that a patient will be "back a hundred times". Issuing these warnings to people with schizophrenia is a professional responsibility. As Carl said, "let them know all the things they will be through if they don't" and "if you don't stop it somehow … from what he is doing."

Randy's message directed to family members, reinforces the concept of the *Paradox of Insight* (it is the stumbling and falling during the *Period of Chaos* that creates insight development). Families must allow self-determination (Schweitzer, Zwack, Weber, Nicolai, & Hirschenberger, 2007) and be tolerant of the more paradoxical, repeated stumbling and falling in order for accountability, personal growth, and maturity to evolve:

> … my mom would do absolutely everything for me and it would never give me a chance, you know? The doctors would tell her to, Leave him alone and let him do his thing and let him grow up. And it never really changed until my mom died. … This is really when an eye opener (happened) …

There was some divergence of opinion amongst participants about whether people can actually learn from the mistakes of others. Hannah believed that she had to learn from her own mistakes, but hoped that others would not have to make the same mistakes. Elly was rueful about her mistakes, and thought that, given the right support, people could benefit from the mistakes of others. While this divergence of opinion existed, all narratives portrayed the hope that others could learn from the participants' mistakes. Again, they wanted to use me, the researcher, to be the messenger to warn their peers not to make the same mistakes that they had: "take your medication", "don't worry about the illness hindering you", "you can have a more carefree life", "get help", "choose your friends wisely", "listen to your doctor", "your family can see things better than you can", and "take responsibility for yourself".

Several participants issued blunt, graphic warnings to their peers regarding the potential consequences of not taking medication: "you will get beat up if you are not careful", "you can get raped", "you will be get into an abusive relationships", "you might get lost", "you will be sorry", "they will grab you, they will beat you, people will be mad at you", "you will go to prison", "you might stab someone", "you will

hear voices", "you will hurt someone", "it is like hurting yourself", "they will attack you, you can die", "it is too dangerous", "this is a warning", "pay attention", "if you want to relapse, go off medication ", "commit suicide", "you will wind up dead", " it is time to grow up". Such were the voices of experience citing the dangerousness of medication non-adherence; they did not understate the degree of dangerousness involved.

The participants also used devices of overstatement in embroidering their warnings to convey the seriousness of their message: "they will come to hospital a *hundred time* times", "*forever* trying to get me to work", "spend *all* your money", "*all* I did was sleep", "running *all* over the place", "*a lot"*, " *all* the time", "if you don't want to do *all* these things", "goodbye to *everybody"*, "*absolutely nothing"*, "*never* give me a chance", "a *long* hospital stay", "I would go off medication *all* the time", "*everything* was done for me". The use of embellishment highlights the severity of their intercessional warnings.

14.5 Personality

> Psychiatrist 2: I think that perhaps we should change the angle and say that insight into schizophrenia has very little to do with schizophrenia but actually has to do with temperament and personality. And if you knew what someone's pre-morbid personality structure was, perhaps that will give us a more accurate prediction of their ability to have insight.

Personalities were revealed through the narrative analysis. Dinzeo and Docherty (2007) provide evidence that the unique characteristics of the individual patient play a role in the development and trajectory of the illness and recommend further study on the effect of temperament and personality. Berenbaum and Fujita (1994) conclude that schizophrenia is associated with higher levels of peculiarity and neuroticism, and

lower levels of extraversion. Torrey (2005) notes the characteristics that stand out in those who have most successfully battled their illness. “One is the person’s underlying personality characteristic of being a fighter, the (other is the) kind of person who never gives up. … Such individuals are probably born with this trait” (p. 14). Evaluation of the transcripts using personality as a theme in the analysis uncovered personality traits that may provide clues to recovery.

Some personality types are risk factors to recovery (Marlowe & Sugarman, 1997). For instance, people with higher levels of neuroticism, and lower levels of extraversion and agreeableness tend to utilize more avoidant coping styles (Lysaker, Wilt, Plascek-Hallberg, Brenner, & Clements, 2003). Some risky personality traits revealed in this study were those of rebelliousness, addiction, and perfectionism. Carl referred to his hard-headedness. This appears to include traits of stubbornness, rebelliousness, and aggressiveness. These traits led to “learning the hard way”. Zack admitted he was rebellious and avoidant in personality style; initially, he did not seek help for himself. Randy referred to people who “don’t want to help themselves; they want to lead the ugly life”. They are perhaps oppositional or defiant of authority. Many spoke of their addictions and addictive personality style that also led to “learning the hard way”. Carol was cheeky and abrupt and had an abrasive quality to her that undermined her relationships with her family, thus, at times, cutting her off from supports. Art spoke about “doing too much” prior to his first break which may be evidence of an over-achiever. These personality styles may contribute to not achieving balance in their lives, thus exacerbating the illness. On the other hand, while initially these appear to be risk factors, the stubbornness and tenacity of a “fighter” may actually be protective factors that eventually lead a person to recovery.

Protective factors of personality may be those of willingness to rely on others when in need, or to be "interdependent". With Sarah, there was evidence of a capacity to rely on others, as she relied on a family care provider to assist her. Elly also appeared to be interdependent, as she relied on the support of her physician, boyfriend, and family. Sam, Olive, and Hannah's personalities suggested independence and determinedness, while Irene's personality was outgoing, as she loved to cook and host dinner parties for her friends, thus engaging in social connectedness. Henry's personality was entrepreneurial. Prior to the illness, his goal was to become a property manager, and despite his illness, he still owned a home-based business. He had integrated his innate personality with his illness, which may have assisted in maintaining strong self-esteem and been a protective factor from relapse.

Personality traits appear to have some relevance in term of risk and protective factors in schizophrenia. Thus, patients who have the two characteristics of stubbornness and insight into their illness are those overcoming their illness (Torrey, 2005). More research into personality may assist in helping us understand how and why a person preconstructs, constructs, reconstructs, and deconstructs dangerousness.

Finally, participants used strong words to describe themselves during their period of resistance and "learning the hard way". They called themselves "weirdoes" and used a sarcastic tone as they called themselves "smart" or "stupid", "unreasonable", "hard head", "party person", "violent", "drunk", "sick", "dirty", "an endangerment", "nasty", "schizophrenic", and a "bum". In the narrative context, the use of these derogatory words could be seen to be a device by the participants to make an example

of themselves and, thereby, emphasize a warning to others not to follow the same path.

Emotion plays a role in understanding insight development and coping (Horan & Blanchard, 2003). Participants used the language of emotion to express their feelings during their *Periods of Chaos*. This meant they not only used words such as, scared, frustrated, fearful, sick, stressed, anxious, sad, suicidal, depressed, frightened, and apathetic, but they elaborated these in a storied context in order to warn of the despair associated with the cycles of non-adherence to treatment. Their capacity to do so shows that the participants are emotionally intelligent; they were able to use these words within a narrative story, rather than as a static device for demonstration. "Good story making is a heuristic process that requires skill, judgement, and experiences … (and that) experiencing the self as a well-functioning unit is highly dependent upon the ability of the individual to construct an integrated and coherent narrative about the self" (Saari, 1991, pp. 142-143).

14.6 Narrative Analysis

Narratives are important units of discourse as they allow for the construction and expression of meaning and how we make sense of our experience. The narrators in this research used the researcher as a medium to carry messages of failure, hope, and instruction from experienced people with the illness to a newly diagnosed person with the illness. In addition, the researcher was used to pass messages to mental health practitioners and to family members. These messages helped the participants re-author their early failures into potential hope and recovery for others.

However, narrative analysis is also an aid to evaluating theory. In narrative analysis, the findings or theory are drawn from the data of the research, and in the discussion, must be interwoven with the relevant literature, which will confirm or challenge the findings of the researcher (Holloway & Freshwater, 2007). The development of theory produced from the life stories of people with the illness can create a collective theory (Keady & Williams, 2007). Collective theory is based on the personal stories of the people involved; the "reading" of those stories to find connections, agreement, similar plots, modification; and moves from personal stories that "agree", or fit within, a macro collective theory. The findings chapters of this thesis (Chapters Eight to Thirteen) and the narrative analysis described in this chapter have used detailed evidence from the data to develop a collective theory. A collective theory can be presented in a narrative statement. This narrative statement of the study reads:

> I am stubborn and society determines when I am too dangerous to myself or others, but no social construct of dangerousness assisted in my insight development. Rather, my insight was developed by my meaning making of an event that carried dangerousness to me or had significant consequences for me. In fact, I have been able to reconstruct that meaning making over time thus preventing re-occurrence of the dangerousness. I now want to assist my peers with the illness by carrying this message, through the researcher, into the world to give hope to others in a lasting way.

These narrative statements give us the *Theory of Dangerousness*. Objectively, the *Theory of Dangerousness* is articulated in this way:

> Insight is developed in a person with schizophrenia when an event occurs directly related to the illness that is perceived as dangerous or as having serious consequences to self or other. This perception of dangerousness triggers the development of insight, and when this perception endures over time, it prevents relapse of the illness.

Therefore, narrative analysis can create collective theory.

When evaluating narrative research, dependability, credibility, transferability, generalizability, and confirmability determine research rigor (Holloway &

Freshwater, 2007). This research should withstand an "audit" of its methods (p. 112) as solid evidence exists within the data. Augmenting the data from participants' narratives are the voices of those who lived and worked with them. At least according to the New Zealand inter-rater focus group, the findings appear to be transferable to similar situations with similar types of participants, and to have applicability and generalizability to others with chronic illness. Future studies replicating the findings together with testing of the theory in everyday direct practice, may confirm the *Theory of Dangerousness* as well as the process of insight development. Layering a narrative analysis upon a grounded theory analysis and arriving at similar conclusions is a way to determine if similarities emerge. In this study, narrative analysis supports the grounded theory analysis and development of the *Theory of Dangerousness*.

14.7 Conclusion

This chapter has articulated the result of a narrative analysis layered over the grounded theory analysis. This narrative analysis looked at the cycles and patterns of the illness, discussed the events that turn the person from illness to recovery, and the messages and warnings people in the study delivered to their peers. Participants used stories and devices of literature, such as vignettes, imagery, and similes, to tell their stories. Using merely a grounded theory analysis, the researcher might have missed the similarities and parallels evident in the narrative analysis. Using a multi-method analysis may serve to "deepen and enrich" (Bloor et al., 2001, p.13) understanding of insight development. This appears to lend credence to the theory developed from this research.

This chapter also concludes the reporting of the findings from within the research data of this study. Rich findings were gleaned from the narratives of the participants, who, in the opinion of professionals, were people with schizophrenia who possessed good insight into their illness. The findings reveal that there is a process to insight development through a *Period of Chaos*, a *Dynamic Period* of learning and growing, and, finally, a *Period of Wisdom*. The *Period of Chaos* is halted by a significant event; meaning making of this event concludes it is too dangerous not to initiate change. This is followed by a long period of learning and growing and it is here, in the *Dynamic Period,* that insight and *C.L.A.R.I.T.Y.* are developed. This *Dynamic Period* engenders the birth of integration, self-growth, and actualization in the *Period of Wisdom*. The fear (*Fear Factor*) of returning to the *Period of Chaos* is a protective factor that prevents relapse back into the dark swirl of chaos. In addition, there are *Four Phenomena of Influence*: losses, barriers, relationships, and spirituality, all impact both positively and negatively upon the process.

Process is important to the development of theory. The identification of a process is an essential feature of theory building: "Theory without process is missing a vital part of the story – how the action/interaction evolves" (Strauss & Corbin, 1994, p. 179). The following chapter will discuss the meaning of the data and provide an overarching theory deducted from, and explanatory of, the data.

CHAPTER FIFTEEN DISCUSSION

> Constructing approaches to research inquiry that build knowledge with people with long-term conditions and cast them as equal partners in the theory building process is not an easy task …. what is important is that the presented theory makes sense to, and is owned by, those it purports to represent. (Keady & Williams, 2007, p. 35)

15.1 Introduction

The rich findings from the research data provide opportunity for detailed discourse on the meaning and implications of these. According to Creswell (1998), "the centrepiece of grounded theory research is the development or generation of a theory closely related to the context of the phenomenon being studied" (p. 56). This discussion chapter presents the overarching theory that was derived and developed from the research interviews and uses Polansky's (1986) tools for analysis to determine the value of this theory. Additionally, the discussion encompasses a closer examination of the concepts of self-determination, dangerousness legislation, and the efficacy of therapeutic jurisprudence.

15.2 Theory Development

Social work theories are critical to improving assessment and service delivery, and challenge social workers to share responsibility for the development of theory to guide practice (Healey, 2005). The final stage of grounded theory methodology is to create an overarching theory to explain the analysis of the research. In his article entitled, "There is Nothing so Practical as Good Theory", Polansky (1986) concludes that the goal of all research is to advance theory, especially theory that drives practice. His paper, initially read at the University of North Carolina School of Social Work in 1983, cites two properties and several sub-properties of what constitutes good theory.

Firstly, he posits that *theory is practical* and, therefore, saves and mobilizes energy; selects attention; articulates the learning of those who have gone before; and constitutes one's own and client's protection against his or her own unconscious. Secondly, he asserts *good theory is dynamic* and, therefore, simplifies one's life, is preferably non-obvious; lets one go beyond known facts; hits the right level of abstraction; is adequately comprehensive; and, finally, good theory tends to elaborate (pp. 5-11).

This study was rich in findings and an overarching theory emerged from this data, being the *Theory of Dangerousness*. The *Theory of Dangerousness* explains the *Process of Insight Development* (*Period of Chaos*, the *Dynamic Period,* and the *Period of Wisdom*) and includes the following concepts: the *Trinity of Crisis***,** the *motivational factor (mf),* the *Paradox of Insight Development*, the *Four Constructions of Dangerousness*, the *Four Phenomena of Influence* to the insight process, and the *Four Types of Insight***.** A full discourse of these theoretical concepts is the focus of this chapter. It must be clarified that dangerousness does not refer to the dangerousness of the individual but rather to the dangerousness *meaning making* the individual applies to any given event, behaviour, or circumstance. In order to provide some context for the discussion, theoretical perspectives from literature on coping with a mental or chronic illness are required.

15.3 Coping

The literature provides contextual information around concepts of coping and appraisal of a situation. A significant problem with the coping research in psychiatry is the lack of clear definitions of coping behaviours, understanding of their

prevalence, and of their attribution to schizophrenia patients (Ritsner et al., 2006). Coping is defined as a set of cognitive, affective, behavioural, and physiological processes that are consciously or unconsciously used to deal with stress (Vaschenko, Lambidoni, & Brody, 2007). Four basic types of coping are involved in managing a stressful event: cognitive (logical analysis), behavioural (active steps), cognitive avoidance (denial), and behavioural avoidance (acting out) (Moos & Holahan, 2003). The first two are adaptive or positive coping methods while the last two are maladaptive or negative coping strategies. Folkman's (1997) Revised Model of Coping sheds some light on what contributes to the choice between adaptive or maladaptive coping strategies. Folkman asserts that meaning making forms the key task of appraisal following an event. Some events described by the participants in this study were vague, invisible events, however, these events were about them and happened to them. Given the opportunity to recall them to an active listener, many were revealed to be hard hitting and life changing. These are described as "personalizing" (Strauss & Corbin, 1998, p. 173) events that are "hitting at personal identity" (p. 174). When the meaning making of a very personal event leads to appraising the event as a threat, harm, or challenge, the person is then propelled along in the process of problem solving, coping, and recovery.

Alternatively, risky events that are appraised as benign or irrelevant, or where blame is attributed to someone or something else, result in emotional coping that leads to unfavourable resolutions and distressing outcomes (Nilsson, 2007). For example, when the coping strategy utilized in a stressful event is avoidance, distraction, withdrawal, denial, or substance abuse, then nothing is done to change the stressor and there is potential for dangerous consequences (Carver & Scheier, 1994). This

maladaptive coping based on the appraisal of the event leads the person back into the *Period of Chaos*.

Two forms of appraisal take place after an event: primary and secondary (Lazarus, 1993). Primary appraisal (meaning making) is determining "what, if anything is at stake", and the intensity of emotion is likely to be related to the importance or motivational strength or "whether an encounter is deemed as beneficial or harmful (threatening)" (Nilsson, 2007, p. 9). Secondary appraisal of a situation involves the attribution of blame or credit and consideration of who, if anyone, is accountable for the harm or benefit. In addition, Nilsson (2007) defines the coping potential of a person as their belief that they can influence the person-environment relationship and their ability to appraise future expectations or make change. This appraisal of blame and credit, the belief they can influence the environment and the ability to look into the future and make change, is the subsequent problem solving that is considered coping. It is the "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). Adopting a positive reinterpretation style of coping is a significant factor in reducing distress. Interpretation and construction of meaning are the key tasks of recovery (Cooke et al., 2007).

This study identified four cognitive constructions of dangerousness (the *Four Constructions)* during the recovery process: *preconstruction, construction, reconstruction,* and *deconstruction*. Examples include repeated maladaptive meaning making that took place, such as overconfidence in judgements and the impaired

ability to self-reflect (Bora, Erkan, Kayahan, & Veznedaroglu, 2007). People in the study jumped to conclusions about why they were in difficult circumstances and blamed others for their misfortunes. During the *Period of Chaos*, they did not construct events associated with relapse as dangerous; therefore, *preconstruction* of dangerousness was present: their primary appraisal was either that there was no risk or harm to themselves or others, or that they were not responsible for any harm. They blamed others for the situation or credited the actions of others for the situation; no personal responsibility was taken. However, once people in the study appraised the events such as committal to a hospital or prison, or a rape, as dangerous this led to their recovery. It was their own appraisal, meaning making, or *construction* of dangerousness that made them believe they could influence the person-environment relationship and make positive change. Their primary appraisal determined that what was at stake was, for example, their own life, the life of someone else, an important relationship in jeopardy, or that incarceration or hospitalization was likely or imminent. All these consequences were deemed dangerous. Once the event was deemed harmful or dangerous, people were motivated to make secondary appraisals. They attributed blame to self and believed, with shaky confidence, that they must henceforth influence the person-environment relationship, and, finally, they took control over, and responsibility for, their future expectations.

If one is accountable for bringing about stress, one might also be in a better position to consider clearly what to do about this. At first glance, appraisal of self-blame, or what Janoff-Bulman (1979) describes as "behavioural self blame", may seem negative or pejorative. However, when the concept is reframed as a taking of personal responsibility it becomes clear that this has the potential to lead to solution-focused

coping (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). In fact, problem-focused forms of coping and positive reappraisals appear associated (Aldwin, Folkman, Schaefer, Coyne, & Lazarus, 1980; Folkman & Lazarus, 1985). Following the event, the people in the study deduced dangerousness following appraisal of the event, and by taking personal responsibility for this dangerousness, this led to problem-focused coping. Dangerousness appraisal flows from the repeated cycles of relapse and promotes insight and recovery. This phenomenon is the *Paradox of Insight Development*; that painful stumbling during the *Period of Chaos* is actually tumbling the lock on insight development.

In addition, and of importance, Lazarus and Folkman (1984) conceptualize coping as a "cognitive-motivational-relational process; cognitive in that it involves knowledge and appraisal, motivational in that it relates to the perceived status of the individual and relational in that it involves an interaction between the person and the environment" (as cited in Nilsson, 2007, p. 9).

This conceptualization gives credence to the *Trinity of Crisis*: Event, Construction, and Hearing a Connection. These three concepts are now explained. An event takes place (*Event*). There is a cognitive appraisal of this event (*Construction*) whereby the person makes meaning of the event's dangerousness to him or her. The beliefs the person holds about their difficulties "are a powerful influence on affect and behaviour" (Kinderman et al., 2006, p. 1909). The event evokes a new belief about their illness. The construction of a new belief of "dangerousness" is motivating and weakens the membrane of denial. Motivation is an internal state or condition that serves to activate or energize behaviour and give it direction that leads to successful

adaptation (Velligan et al., 2006). The event and the construction of dangerousness create the motivation for wellness. The motivation creates permeability in the denial and enhances opportunity for receptivity. The receptivity, called *Motivated Receptivity,* allows absorption of an interventive relational message (*Hearing a connection),* or a meaningful message from someone that make sense to the person with the illness, that builds recovery. This *Trinity of Crisis* is the mechanism or the *motivational factor (mf)* that results in a decision to change for the purpose of recovery. Similarity and conceptual overlap exists between the *Trinity of Crisis* and the cognitive-motivational-relational process described by Lazarus and Folkman (1984). In addition, a psychotic episode can be a form of "personal crisis" which can hold the potential for improvement and growth "through the individual's active efforts at finding meaning in the experience and moving toward recovery" (Roe & Chopra, 2003, p. 341).

The meaning making of dangerousness is a potent, but invisible reactor of the recovery process and moves us away from linear behaviourist explanations suggesting there is a unidirectional sequence of causes and effects for human and social processes. Instead, Guastello (1997) describes the concept of the *Butterfly Effect* borrowed from complexity and chaos theory that applies to the invisible changing effect of dangerousness meaning making:

> A non-linear relationship between two variables is one where an incremental change in one is not met with a proportional change in another. Rather, a small change in one variable, at the right place and time, can produce a large effect elsewhere in the system. Alternatively, a large change in one variable could produce a negligible impact on another. Although non-linear phenomena abound in nature, they are often treated as quaint curiosities in a relentlessly linear world view. (p. 345)

A small thought creates energy potential for significant change.

The construction of dangerousness contains a second and equally important aspect: the meaning making of dangerousness must endure and prevail over time. Therefore, the event and its consequences must be remembered. "For an intervention to have an impact, the basic messages have to be understood and accepted by the patient, related to his or her own problems as well as remembered and integrated into every day life" (Lincoln, Wilhelm, & Nestoriuc, 2007, p. 242). Over the lifespan following the event, the dangerousness memory must remain and be constantly reconstructed as dangerous to the person (*mf*), hence a protective factor against relapse. *Reconstruction* of dangerousness is then a protective factor assisted by the relapse experience of the individual; experience is a dimension of *reconstruction*. This fear or belief that risk of threat is involved may actually be a protective factor in reconstruction of dangerousness. *Reconstruction* may be why people with substance abuse issues continue to attend Alcohol Anonymous or Narcotics Anonymous meetings, long past the active addiction. The meetings serve as a tool to continually reconstruct dangerousness for them. In the same vein, long-term follow-up with a mental health worker may assist in reminding the person with the illness of the dangerousness of medication non-adherence. While these protective factors serve to enhance one's ability to cope, they are not entirely preventative in avoiding relapse. For researchers, therefore, the search is not just for the protective factors but also for the development of situational mechanisms or processes that produce resilience (Rutter, 1987). *Construction* and meaning making of the consequences of dangerousness and relapse (*reconstruction*) are part of the mechanism that sustains and protects from relapse.

A dysfunction in the dopamine system may potentially interfere with the patient's ability to appraise or remember dangerousness. Barch (as cited in Wittmann & Keshevan, 2007) reports that cognitive deficits, particularly impaired working memory, may make it difficult for patients with schizophrenia to "retain the image of the goal for which to remain motivated" (p. 164). Without the retention of the image or reconstruction of the meaning of danger, *deconstruction* takes place; a forgetting, a meaning making that is watered down to less dangerous, less risky, less perilous. It is due to this deconstruction that the person re-enters the *Period of Chaos*. When a person is unable to sustain the meaning of the event there may be a cognitive inability to "hold on" to the meaning making of dangerousness. This concept is similar to the obese person losing weight, but over time not being able to sustain the weight loss, despite the consequences, as they lose the meaning making of the event or memory of what triggered the weight loss in the first place. Risk factors for deconstruction include loss of relational support, intensity of religious preoccupation, stress, and stigmatization. Therefore, greater stress/distress created during the *Period of Chaos* may precipitate dangerousness meaning making and a subsequent positive coping. Highly anxious people are more likely to judge the risk of an event or threat higher than non-anxious people (Mitte, 2007). Paradoxically, prevention of stress/distress may actually impede, retard, and hamper the recovery process and may need to be considered for those who "learn the hard way".

A systemic review of the literature concludes that the majority of studies support the assumption that insight is associated with adherence to medication (Lincoln et al., 2007). However, when insight development is viewed as a process along a continuum from no insight to full insight, there is evidence that insight development actually

begins *prior* to or at least very early after beginning medication at the *Trinity of Crisis*. The findings from this study indicate that while medication, in particular the right medication, contributes to the development of full insight, the seeds of insight were planted by the cycles of relapse during the *Period of Chaos* and fertilized by the *Trinity of Crisis*. Fuller insight development grew from there.

Since dangerousness meaning making of an event leads to recovery, professionals must focus on assisting the person to construct dangerousness meaning after an event. Discourse and practice need to focus on whether a person needs to undergo chaos and "hit bottom" in order to construct dangerousness, or whether it possible to "elevate the bottom" and accelerate the construction of dangerousness to take place with their first psychotic episode.

While recovery is a process, "it is not a perfectly linear process. At times our course is erratic and we falter, slide back, regroup and start again" (Deegan, 1988, p. 15). Full extinguishment of relapse does not seem possible. Deconstruction is always lurking and reinforcement of meaning making may be a life-long requirement for both the individual and the community that supports the individual. Clues to deconstruction were evident in the research. For instance, in the participant focus group, Irene talked of her confusion about why, despite a long period of recovery, she still toyed with the idea of going off her medication from time to time. In his poignant reply to her during the focus group, Art provided a strong clue regarding why deconstruction happens:

> When I stopped taking my meds, it was directly to do with my self-esteem. There is a part of me that still says I am not good enough. I have to take these pills. I am not the same as him, this will come back again. It is a cycle. A cycle of sabotage will happen every five years and that had to do with my self-esteem.

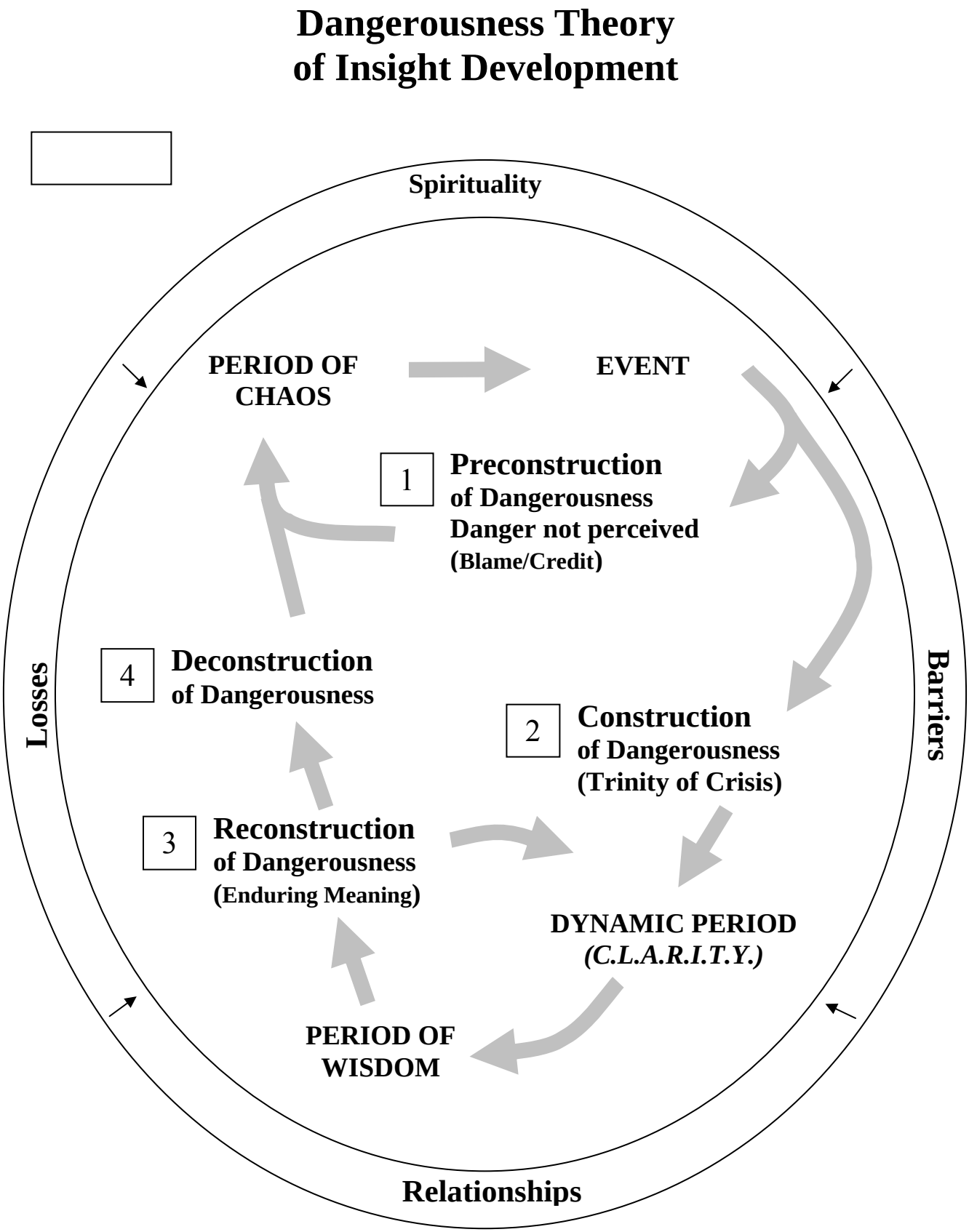
Hannah agreed that when a lack of acceptance of self occurred, her self-esteem was undermined: “I did not accept myself for who and what I was.” This lack of self-acceptance can lead to deconstruction.

These short extracts provide practitioners with three important pieces of information. Firstly, self-esteem may be what both underpins and undermines recovery and the continuous reconstruction of dangerousness. Secondly, digging deeper into this piece of text, another clue emerges: what undermines self-esteem are the *comparisons* the person with the illness makes between him or herself and others. “I am not good enough”, “I am not the same as him”. These comparisons are examples of cognitive distortions: a remnant of the belief that he or she is flawed, the belief that others are better than he or she is. Finally, Art’s statement describes a cyclical nature to these cognitive distortions; there is no termination or extinguishment of the beliefs, but a waxing and waning of the beliefs. These pieces of text provide us with information from which we can build useable intervention tools to shift these cognitive distortions. This is “self-stigma” where the person internalizes public stigma with the effect of harming the person both cognitively and behaviourally (Corrigan & Wassel, 2008). A correlation exists between perceived stigma and self-esteem. In addition, self-esteem levels may be related to the ability to do things as well as others, to feel useful and experience a feeling of self-respect (Berge & Ranney, 2005). Maintenance of self-esteem may be pivotal in underpinning and supporting the ongoing reconstruction of dangerousness meaning making, while loss of self-esteem has the potential to undermine and deconstruct this dangerousness meaning making. These findings are consistent with other findings that paranoia and persecutory delusions are associated with self-esteem (Meissner, 1981; Thewissen, Bentall, Lecomte, & van Os, 2008);

diminishing self-esteem is related to an increase in vulnerability to paranoia and voices. Building and maintaining self-esteem may be the bedrock of the insight process, and the maintenance of the therapeutic alliance is critical to that process. In fact, given the real and grave impact of mental health stigma, it is the "duty of the case manager to work towards decreasing stigma as a whole" (Berge & Ranney, 2005, p. 143).

Meaning making of dangerousness is a cognitive construction. Therefore, within the data, *Four Constructions* of meaning making of dangerousness during the *Process of Insight Development* were evident*: preconstruction* of dangerousness, *construction* of dangerousness, *reconstruction* of dangerousness, and *deconstruction* of dangerousness. Figure 1 highlights these constructions. This figure constitutes a "logic diagram" or visual model of the culminating theory developed from the study (Creswell, 2007). These constructions are intrinsic to the flow of experience for those with schizophrenia as they combine "both the meaning of the proximal past as it impacts on the constitution of new meaning in the present and the imagined future toward which the present experience is directed" (Davidson, 2003, p. 105). The *pre-construction, construction, reconstruction,* and *deconstruction* of dangerousness are the *motivational factors (mf)* across the continuum of mental illness recovery. These continuums are embedded within a process of insight development and recovery.

Figure 1: Theoretical Logic Diagram



15.4 Recovery Processes

Insight development in schizophrenia is embedded in the recovery process. At this time in the development and conceptualization of recovery, no single set of criteria for defining recovery has been determined (Leucht & Lasser, 2006). Many models of recovery processes exist. However, they do not explain how movement from one stage of change to the other is triggered. The motivational factor (*mf)* is missing. In this study, the motivational factor (*mf)* explains how people move from one stage of recovery change to another. The *Trinity of Crisis* is the combustion process or motivational factor (*mf)* that projects people into new stages of recovery:

> … essential impairment in schizophrenia appears to be focused at the intersection of cognitive and motivational processes, where the consequences of actions serve to shape changes in behaviour leading to more successful adaptation. (Velligan et al., 2006, p. 481)

Examples of recovery processes are described to demonstrate that the *mf* is missing at this intersection of cognition and motivation. The STORI (Stages of Recovery Instrument) documents five stages: *moratorium* (loss and hopelessness), *awareness* (hope), *preparation (*taking stock of strengths and weaknesses and developing skills for recovery*), rebuilding (*actively working toward positive change and control over one's life*)*, and *growth* (living a meaningful life*)* (Andresen, Caputi, & Oades, 2006). This process mirrors aspects of the process in this study, but is devoid of the significant and necessary motivating event/factor *(mf)* that breaks the ambivalence and moves a person from the moratorium stage to the awareness stage. Similarly, DiClemente and Prochaska's Transtheoretical Model of Change (1982) has been a useful heuristic device for conceptualizing individual recovery (Onken et al., 2007), as it describes a series of five stages through which people pass as they change behaviour (Miller & Rollnick, 2002). These five stages also bear similarity to this

study's findings: *precontemplative, contemplative, preparation, action,* and *maintenance*. However, again, the *mf* is missing to describe the motivational dynamic that moves someone from one stage to the next.

Koithan et al. (2007) report a process of "whole person healing" and identify a developmental course that moves a person with a chronic illness from being "stuck", to "unsticking", to "unstuckness". They describe a "point in time or a particular instance where shift/change occurred" (p. 662) or where the "unsticking" began. Again, there is no theoretical prediction of what is the particular instance or specific catalyst propelling the person out of the *Period of Chaos*. Corrigan, Giffort, Rashid, Leary, and Okeke's (1999) Recovery Assessment Scale (RAS) found five components in a stage model of recovery: personal confidence and hope; willingness to ask for help; not being dominated by symptoms; goal and success orientation; and ability to rely on others. Young and Ensing (1999) developed the Mental Health Recovery Measure (MHRM) and outlined three phases and six aspects of recovery: Phase I, Overcoming stuckness; Phase II, Discovering and fostering self-empowerment, Learning and self – redefinition, and Return to basic functioning; and Phase III, Striving to attain overall well-being and Striving to reach new potential. While, these models align neatly with the insight process proposed in this study, neither of these recovery models contain the *(mf)*, and, therefore, they do not offer an explanation for how and why people move, for example, from Phase I to Phase II, or from preparation to action. They do not offer the totality and complexity of the findings contained in this study.

Roe and Chopra (2003) report a recovery process that begins with temporality, the longitudinal nature of human coping over time. This is followed by the meaning which individuals assign to their illness that directly influences how they respond and cope with this illness and, finally, integrate their self-concept. Roe and Chopra's process of recovery also has characteristics similar to those found in this study, but again it seems to lack the explanation of the contingencies between, "Unanticipated or unplanned events that change conditions that can call on some sort of action/interactional (problem solving) response to manage or handle them" (Strauss & Corbin, 1994, p. 181). The path taken after an event is contingent on people's meaning making of the event. The *Trinity of Crisis* is the *mf* that moves people out of the *Period of Chaos* into the *Dynamic Period,* thus, perhaps, building upon and adding to the recovery models already in place.

The construction of dangerousness is both the instigator and protector of recovery: it propels the person into the dynamic and wisdom phase, and it is the constant *reconstruction* and remembering of the dangerousness that maintain recovery and prevent revisiting the *Period of Chaos*.

15.5 Theory is Practical

Polansky (1986) believes that theory has to have practicality. For instance, utilizing a theoretical model saves energy as it gives practitioners and patients alike a guide or a mental map of thinking before acting; thus they are not wasting energy trying this and that intervention. Applying the *Theory of Dangerousness* has the practicality of saving energy for both health care worker and patient as they can avoid the multiple trial and error attempts to overcome difficulties. The practitioner has a knowledge map to

assist the patient in their construction of dangerousness early in the *Period of Chaos*. Practising from a credible theory base mobilizes energy and is persuasive, even allowing a "touch of zealotry" (Polansky, 1986, p. 4). Zealotry comes from the root word "zeal", meaning passion or ardour; eagerness or enthusiasm (Oxford English Dictionary, 1985). Thus credible theory allows the worker to present interventions with eagerness, enthusiasm, and conviction of their efficacy, thereby decreasing worker alienation, burnout, or "clinician illusion" (Bassett & Reader, 2005, p. 16). A "clinical illusion" refers to the belief that people with schizophrenia simply do not recover. Instead, good theory can help professionals become "more optimistic, positive and hopeful in their work with people who experience mental health problems" (p. 17), and they can do this through a recovery-oriented approach (p. 18). The *Theory of Dangerousness* can provide workers with a credible theoretical base within which they can practise with conviction and hence be more persuasive and influential in their recovery interventions.

In February, 2008, in New Zealand, four inter-rator focus groups were held to present the findings of this study. An agreement questionnaire (Appendix J) was completed by the individuals in the groups as a way to determine if, a) the research made sense, and, b) if the research findings could guide practice. The scores presented in Appendix K indicate that the constructs of the *Theory of Dangerousness* made sense and were thought to have potential to guide professional mental health practice by the practitioners who participated in these four inter-rator focus groups.

These responses suggest that the *Theory of Dangerousness* may be a worthwhile theoretical tool to guide intervention. It may allow workers to apply theory with some

conviction by using a process, constructs, and useful language to predict and plan the course of recovery.

Polansky (1986) asserts that theory selects attention. He explains, "As humans we try not to be aware of something we do not want to know … self imposed blindness to ward off knowledge that would signal calamity such as a spouse's unfaithfulness"; but the converse is also true, selective attention also exists: "Clothiers notice styles, carpenters the fit of corner joints, each of us sees what we want to see" (p. 6). We see these things because we consider them helpful and it is positive to notice them. Theory affects workers' perception and allows them to bring to consciousness what they see. They can then articulate what they see back to their clients. The *Theory of Dangerousness* can provide a perception and a lens through which the worker can see and articulate dangerousness, therefore, guiding practice.

Theory articulates the learnings of those who have gone before (Polansky, 1986). Development of a theory is built upon the research, practice, and experience in the field of study. Good theory condenses this experience, transmits, and builds to further research and implementation of evidence-based practice. The *Theory of Dangerousness* is built upon a thorough literature review and a synthesis of all found research literature on, and aligned to, the concepts of insight and recovery. In addition, it is built upon the stories of real people with schizophrenia and the data gleaned from this research project, which subscribed to rigorous methodological procedures. Polansky (1986) reminds practitioners that theory is one's protection against one's own unconscious and that we are subject to motives and feelings that can interfere with the helping process. Theory bolsters professional discipline and

assists practitioners to avoid the use of "eclecticism that leaves one's choice of concepts at the mercy of one's own unconscious" (p. 8).

Applying the *Theory of Dangerousness* can reframe the frustration that comes with watching the destructive cycles and chaos that are often associated with mental illness. These cycles may be a necessary part of the recovery and insight development process, and practitioners, armed with that knowledge, are more empowered in their interventions and can counter hopelessness, including in family members. Polanksy (1986) believes that theory also offers the client protection against his or her unconscious and he warns practitioners to be observant of the client's unconscious defence mechanisms and to use theory to expose these. The *Theory of Dangerousness* can be used to expose the client's denial of their mental illness and the cycles during the *Period of Chaos* by a cognitive magnification of the dangerousness of their lifestyle.

15.6 Theory is Dynamic

Secondly, Polansky (1986) posits that theory is both dynamic and predictable and that it contains information about cause and effect in relationships. "Successful prediction is the most trusted test of the validity of a theory" (p. 10). The *Theory of Dangerousness* may have predictive value by allowing practitioners to effectively "plot out" the position of the person along the insight development continuum and to evaluate the likelihood or readiness for change. From this graphic portrayal, the professional can predict what needs to occur to advance the person along the recovery process. If the practitioner can introduce, influence and obtain an acceptance or "buy-

in" of the dangerousness of the event from the person with schizophrenia, the effect of taking control over one's health should follow.

Another property of good theory is that it simplifies one's life (Polansky, 1986). Good theory is parsimonious; it is the result of the boiling down of all the information until rendered solid. The *Theory of Dangerousness* is the simplest or core element of the research. Good theory is not only simple, but also non-obvious. Polansky points to the concept of the paradox to explain the non-obvious. Paradox is defined as:

> a statement or tenet contrary to received opinion or expectation, often with the implication that it is marvellous or incredible, sometimes with unfavourable connotation, as being discordant with what is held to be established truth and hence, being absurd or fantastic. (Oxford English Dictionary, 1971, p. 2072)

The *Theory of Dangerousness* and insight development demonstrates that it is the paradox of stumbling and falling during the *Period of Chaos* that leads the person to construct dangerousness and to insight. The paradox is also that we intervene for the *safety* of the person, when, in fact, our interventions need to create a perception of *dangerousness* within the person. *Dangerousness Theory* clarifies that the stereotypical social defining of dangerousness is the antithesis of what develops insight and wellness in people with schizophrenia. Dangerousness needs to be constructed by the person with the illness to begin and sustain recovery.

Polansky (1986) explains that theory that is not applicable to case work is not valuable; that the holistic world of the researcher/practitioner should match the theory, in order for it to have applicability. Good theory hits the right level of abstraction. Polansky asserts that theories that are irrefutable are not theories about empirical events, but circular definitions that permit generalities. The *Theory of Dangerousness*

is circular and dependent on the meaning making of the event. The event itself can have many generalities that may range from the danger of losing one's shelter or losing the trust of a loved one, to something more serious, such as the danger of murdering someone. Good theory must accommodate the range of events that occur in life and allow the definition and meaning making of dangerousness to evolve and change within each person, at each stage of their illness.

Theory must be adequately comprehensive, taking into account strengths and deficits in a client's abilities and life chances, and must be customized for the particular client. The *Theory of Dangerousness* is flexible and can be adjusted to the needs of each individual. What is perceived as dangerousness by one individual is not necessarily dangerousness to another. Customization needs to take place.

Finally, good theory tends to elaborate. The *Theory of Dangerousness* is not inert, nor merely a descriptive list or dead theory, but may be an "intriguing principle" (Polansky, 1986, p. 13) that has the potential to be extrapolated to all chronic illnesses and other behaviour changes. This principle may have potential to evolve, change, and be extended through new research and evidence-based practice. This recognition that context will change over time, as "there can never be absolute, certain and once-and-forever truth" (Holloway & Freshwater, 2007, p. 111), thus meets the criteria that research is provisional and contextual. Schön (1983) encourages practitioners to be aware of reflective practice that considers that knowledge is continuous and across the experience of both practitioner and client. Polansky's (1986) article is a useful tool to evaluate the *Theory of Dangerousness;* the theory appears to meet Polansky's criteria for testing theory.

Perhaps the time has come for locating the responsibility for the condition of sanity within the sufferers themselves. But rather than a responsibility that implies moral deviance and a need for repentance for their deliberately unacceptable social behaviours, we give the responsibility to the person with the illness to "know best" when dangerousness for them or for others is imminent. Therefore, "it is important that the patient is brought into the dialogue where the meanings of events are socially created. It is more important to hear and try to understand the patient's story as told by himself than to understand events through stories where the meanings are already determined" (Holma & Aaltonen, 1998, p. 261). A discussion on the concept of self-determination is warranted and hence is the focus of the following section.

15.7 Self-determination

> Within client-centred practice, social work has vigorously championed client well-being, strengths, empowerment and mutual partnerships in resolving problems, needs and concerns. It has acknowledged and honoured self-determination and choice within its values system. Social control, on the other hand, epitomizes a different perspective and approach. It aligns with criminal justice and is geared to the protection of society. (Burman, 2004, p. 197)

Social workers have long advocated for self-determination for their clients (Loewenberg & Dolgoff, 1992). Self-determination rests on freedom to make basic decisions for oneself, liberty to determine one's own actions, and to direct one's own life. Self-determination is as much the right of a client as it is of "their non-diagnosed brethren" (Anthony, 2003, p. 1). Yet, social workers also often join with psychiatrists and other mental health professionals in making committal decisions (Levinson & Ramsay, 1979) and may, in fact, feel obligated to do so, given the competing desire to protect the patient from the potential legal, social, financial, and personal ramifications of making "poor choices". "Excessive respect for the abstract notion of

'choice'" (Ferleger, 1994, p. 75) leaves the person with mental illness at risk when they are lacking insight. This is always a conundrum: safety versus choice, morality versus ethics.

Goldberg's (2007) book entitled, *Moral Stealth*, attempts to sort out the conundrum between morality and ethics and suggests we make our assumptions explicit when discussing ethics and morality. Moral and ethical assumptions in practice must be made explicit so outcomes can be measured thus defining practice directions. The gap between safety and choice often creates dilemmas for practitioners. Serbnik, Russo, Sage, Peto, and Zick (2003) recommend instituting directives into practice policies to thwart the use of constraining measures, such as forced medication, seclusion, and physical restraint, in hospitals and crisis centres. These threats to basic rights, as well as the lack of adequate recovery-oriented services, have led mental health advocates to define self-determination as people's right to be free from involuntary treatment, to direct their own services, to be involved in all decisions concerning their health and well-being, and to have meaningful leadership roles in the design, delivery and evaluation of supports and services (National Alliance for Self-Determination, 1999).

It is imperative that social workers are alert to these debates as they continue to evaluate their role with the mentally ill. Barker (1992) highlights the clinical difference between "helpful" and "helping" roles. Helpful roles, she explains, involve intervening on behalf of the person in care and solving problems, whereas helping roles facilitate growth and development (p. 67). These helpful interventions by mental health professionals should not relegate a person to a state of helplessness, but rather reinforce a sense of control and acceptance (Lakeman, 2000).

Bonney and Stickley's (2008) review of over 170 British papers on recovery found that "risk and responsibility" was one of six dominant themes. They note that several authors record that risk can be a predominant catalyst for change and, while painful and hazardous, can also be rewarding. Gilovich and Medvec (1995) explain Lewin's 1951 theory postulating that compelling forces are more effective than restraining forces. Thus, the compelling force of dangerousness meaning making promotes recovery more than forces of restraint such as committal. Therefore, whilst trying to motivate someone to do something, professionals frequently try to "push" the person in the direction they want to go. When what is actually effective is eliminating the barriers preventing them from changing. Forcing treatment may not be a barrier to change or a loss to self-determination if the encouraging and facilitating of dangerousness meaning making, in a non-psychotic way, during a hospitalization can occur. From the study, it appears that assisting people to make this cognitive shift is not only empowering but fosters their self-determination and promotes recovery, thus enhancing their liberties.

The analysis of the narratives of the participants in this research suggests that what really precipitates recovery are individual experiences, feelings, and realizations about dangerousness ramifications and consequences to self and others. Hence, by just "protecting" people from these risks and impacts perhaps we are relegating them to a state of helplessness, thereby, paradoxically "harming" them or at least, blocking and delaying their recovery. Empowerment may be allowing people to "learn the hard way". We may need to take an opportunist approach: when a person is dangerous to self, we commit, treat, and plant cognitive seeds of dangerousness. We can then

respect their decision to “learn the hard way”, if they choose to ignore the warnings of dangerousness and stop treatment following discharge. We can then utilize their experiential stumbles to assist them to create dangerousness meaning making over time.

Anecdotally, it would appear that we also see people with addictions seeking help after an event that has shaped meaning making of dangerousness; and some literature exists to support this. Tucker, Vuchinich, and Gladsjo (1994) found event occurrences began two years prior to the attainment of abstinence by recovered alcohol abusers. Hodgins and el-Guebaly (2000) found that resolved gamblers reported emotional and financial problems that led to treatment. It is useful to follow this section on self-determination with a discussion on dangerousness legislation.

15.8 Dangerousness Legislation

As indicated earlier, most countries have adopted dangerousness legislation policies for committals under the mental health acts, but there is a striking paucity within the literature on the actual definitions of dangerousness. This leaves a considerable margin of subjectivity in the interpretation of the term. What is even more striking is that no literature exists wherein dangerousness from the perspective of the patient has ever been determined. Torrey (2006) reports on society’s concern about violence committed by people with schizophrenia and argues that this is a treatment issue since some laws make committal extremely difficult. He supports assisted treatment. Forced treatment is not emerging as a factor in recovery, but the fear of re-hospitalization is among the events that create meaning making of dangerousness and, therefore, provoke recovery. If the cycles of relapse have consequences that can be assisted to

be felt to have great personal impact, the individual may be more likely to construct dangerousness, and this, in turn, would appear to provoke the recovery process.

Implicit within the relationship between patient and clinician is the therapeutic bond of rapport, acceptance, unconditional positive regard, and empathy. Burman (2004) argues that this bond is damaged when the client suspects the clinician has ulterior motives, such as a primary commitment to the legal system; under these circumstances, trust deteriorates. Leaving confinement to the legal system would remove the physician from the committal process, thereby keeping the therapeutic bond intact. Bassman (1997), both a psychologist and a person who has experienced committal as a mental health patient, agrees and advocates for "separate control and management from treatment services" (p. 241). Social control is not recovery management.

The individual's construction of dangerousness provokes recovery, whereas the social construction of dangerousness (committal) protects the person from harm to self and perhaps to the public. As we move toward more evidence-based practice, we need to determine the outcomes of committal under mental health legislation and, perhaps, advocate for a change in the focus and purpose of committal. Recovery is the desired outcome, but dangerousness meaning making may be the purpose. If dangerous meaning making is achieved, recovery may follow. We also must begin listening to what is dangerousness for people and constructing outcome measures that support evidence-based practice. A move toward a model such as this would invoke a need for greater community resources, such as safe housing, enhanced mental health support teams, low level staffing, and voluntary containment homes where stability can be

offered and where professionals can encourage dangerousness meaning making after a crisis. These types of facilities may ameliorate some of the risk toward the public, yet still allow for client self-determination, and, potentially, "raise the bottom" of what constitutes dangerousness for the person with schizophrenia. This same argument can be applied to the prison system. If dangerousness meaning making is made the purpose of incarceration, then perhaps establishing therapeutic jurisprudence, "putting mental health back in mental health law" (Perlin, Gould, & Dorfman, 1995, p. 80) is possible. This therapeutic jurisprudence may have the impact of assisting people to construct dangerousness sooner by using "procedural fairness, proportionate treatment interventions and minimization of infringements on clients' rights" (Glaser, 2003, p. 152).

Therapeutic jurisprudence may come in the form of mental health courts. There are currently more than 150 mental health courts in the United States and about six in Canada (Churley, 2008). These courts were established in recognition that "regular courts weren't dealing well with the (mental health) populations and were spending inordinate amounts of time straightening out preliminary psychiatric issues" (p. 31). These courts deal with issues of competency to stand trial, a multidisciplinary problem solving approach that includes the judge, duty counsel, psychiatrist, and mental health professionals to develop treatment plans and linkages to the community. These treatment plans need to include legal "teeth" to ensure the compliance with treatment. Perhaps this is a point where dangerousness meaning making can be facilitated as well. This therapeutic jurisprudence is perhaps the way to "reach the right result" for those whose mental illness involves them in criminal matters rather than just "doling out punishments" (p. 32). Canada's first community court is

scheduled to open in Vancouver in late September, 2008, and while this was deemed laudable, concern was expressed that adequate resources were necessary to address underlying issue of poverty, disease, addiction, and mental illness. “It will be a great waste if the government of British Columbia lets this become another story of insufficient access to treatment.” (“Community Court”, 2008, p. A16)

While speculative, this discourse finds some support in findings from this research. It would appear appropriate, therefore, to reconsider the ideology of how we treat mental illness if current practices might, on balance, prevent a timely construction of dangerousness and, thus, fuller or more rapid development of insight. We might, for example, further explore if the change in focus to meaning making of dangerousness in both hospitals and prisons may be a dividing line between helping roles and helpful roles that are often confusing to mental health professionals.

15.9 Conclusion

Recovery models do not fully explain how people move from one phase of recovery to the other. By contrast, the overarching *Theory of Dangerousness* provides a theoretical explanation for what motivates and instigates people’s movement between phases of insight development. A discussion on self-determination and dangerousness legislation was applied to the *Theory of Dangerousness* along with an explanation of its wider potential implications. These implications bear further discourse on dangerousness, dangerousness meaning making, and therapeutic jurisprudence, and may involve changes to intervention approaches. Substantive theory is relevant to the data or subject area studied as it is grounded in research from that substantive area. However, substantive theory may have broader implications, relevance, and applicability to other fields and, therefore, moves toward grounded/formal theory

(Glaser & Strauss, 1967). Formal theory developed from the data is judged on its adequacy, its ability to fit the phenomenon under study, to provide understanding, to be general enough to cover a range of situations but not so abstract that it loses its relevance in the context (Wells, 1995). It is possible that the *Theory of Dangerousness* may meet both substantive and formal theory criteria. The implications of these findings will be fully discussed in Chapter Sixteen.

CHAPTER SIXTEEN IMPLICATIONS FOR POLICY, PRACTICE, FURTHER RESEARCH, AND LIMITATIONS OF THE STUDY

16.1 Introduction

A fully developed theory, in the context of behaviour change, addresses the following questions: Why do people or organizations behave as they do? What motivates them to change behaviour? (Sales, Smith, Curran, & Kochevar, 2006). A theory should provide hypotheses and guidance for action for the individual practitioner and for higher levels of the organization. The implications for policy and practice from this research may create concerns for those interested in the health and welfare of those with mental illness. In light of the research findings, whereby the *Paradox of Insight* appears to suggest at least some persons with schizophrenia "learn the hard way", we, as society, need to reconsider issues of self-determination, incarceration, hospitalization, and therapeutic jurisprudence. As practitioners, we need to ask how we might amend our practice on the basis of these findings. This chapter builds on Chapter Fifteen's discussion of the *Theory of Dangerousness* and examines how this theory might inform policy and practice with the mentally ill, more specifically, social work practice. A significant number of recommendations for further research to help clarify these directions are provided. Finally, this chapter considers the limitations of the research.

A review of the *Butterfly Effect* (Guastello, 1997) and the social worker's influence on change is necessary prior to framing recommendations for policy and practice. The *Butterfly Effect*, mentioned in the Chapter Fifteen, suggests that a small change in one

variable, at the right time and in the right place, can effect large change in other parts of the system. From this research, we see that the small invisible change that results in a positive effect on recovery is the meaning making of dangerousness. This meaning making is a cognitive shift, easily overlooked, yet powerful enough to bring about change that leads to recovery and insight development. Thus, policy and practice interventions must target this spot, following an event, where meaning making of dangerousness is possible.

Social workers have long realized the value of the use of influence. Influence can "produce change, persuade or convince, overcome obstacles, motivate and bring about attitudinal changes" (Johnson, 1989, p. 90). The social worker can influence their client to ensure that, over time, the language of dangerousness is received and subjectively constructed and reconstructed by the client to develop an understanding that not being treated is dangerous to self. Carl invited workers to use their influence through repeated reminders to take medication:

> Now it takes years and years of people repeating it to ya. … Now people have to keep repeating that to ya until it finally sinks in … somehow it's got to sink in to them, by telling them.

Danger is defined as the possibility of suffering harm or injury, cause of harm or injury, the possibility of something unwelcome or unpleasant (Oxford English Dictionary, 2004). It is possible that using words such as danger, dangerous, and dangerousness may be the tool of intervention to assist in the construction, reconstruction, and meaning making of dangerousness. Using language such as dangerousness may have greater impact on keeping alive the meaning making that precipitates change than the more benign, clinical, and unemotional words generally used by health care workers, such as "you will relapse", "you will get sick again",

"you will get ill", or "you will be hospitalized". While these words clinically describe the end result of "going off" medication, they do not clearly describe the consequence to the person that the words dangerous, threat, menace, harm, or risk might convey to them. These emotionally laden words emphasize the personal cost to the person. If language constitutes and constructs reality (Kvale, 1996), then the language that we use in an intervention needs to be meaningful to the person, thereby assisting them in the construction of their reality. In addition, the word danger or dangerous is an interactional word that conveys an environmental context, cause, or link to relapse or to being sick, something outside of self, thus, removing the personal blame of relapse. This interaction between worker and client is an "interaction between two people … an interpersonal situation where the relevant data are constituted by the interaction itself … in obtaining knowledge" (Kvale, 1996, p. 35).

16.2 Implications for Policy

The Chronic Care Model (CCM) of Health (Wagner, 1998; Wagner, Austin, & Von Korff, 1996) acknowledges that people with chronic illnesses are a cost to the health care system. This heuristic model identifies the changes needed in the health care system to improve outcomes for the chronically ill. Specifically, the model states that in order to improve chronic illness outcomes, effective intervention must increase patient confidence and skills, and thus increase the likelihood of appropriate behavioural changes in patients to better manage their health (Glasgow, Orleans, & Wagner, 2001). To support the Chronic Care Model, three policy recommendations are suggested from the findings of this research: greater discourse around dangerousness, a greater allocation of resources for cognitive therapies and psycho-education (both individual and group), and, finally, lifetime professional support for persons with schizophrenia illness. These recommendations require some discussion.

Dangerousness legislation is about protection for the public and protection for the person suffering from mental illness, but recovery does not singularly come about because of the forced treatment through this legislation. Recovery comes from a combination of results of this legislation. Firstly, loss of freedom is seen as dangerous, and secondly, forced treatment opens a window for insight development. We need to have a combined academic and grassroots discourse about how treatment in hospital is not what provokes recovery but, rather, how hospitalization and losing the right to self-determination by forced treatment may be a triggering event that constructs dangerousness and begins recovery for the person. Hospitalization may present an opportunity to assist the patient with dangerousness meaning making which will then promote recovery. This dangerousness meaning making, during hospitalization, may be enhanced through cognitive therapy. The following section will discuss the importance of dangerousness meaning making and the opportunity that both hospitals and prisons have in assisting with this meaning making.

16.2.1 Cognitive Therapy

The influence of advances in cognitive behavioural theories and therapies on working with people with schizophrenia has been limited. Of 1076 articles that have evaluated mental health practices, only 295 (27%) evaluated mental health interventions, and of these only 33% researched psychosocial or psychotherapeutic interventions. In addition, only 4% of the described studies took place in common practice settings (Shumway & Sentell, 2004). Research in practice settings to inform evidence-based practice is strongly urged.

Some research exists focusing on interventions that improve insight in people with schizophrenia: compliance therapy (Kemp et al., 1996), cognitive enhancement therapy (Hogerty et al., 2004), cognitive and psychodynamic approaches (Silva, Kim, Hofmann, & Loula, 2003), cognitive therapy (Silva et al., 2003; Steffin, 2000), cognitive behavioural therapy (Sensky et al., 2000; Thornicroft & Susser, 2001), brief cognitive analytic therapy (Kerr, 2001), and psychological therapy (Jakes & Rhodes, 2003). Cognitive remediation, developed to address cognitive function in schizophrenia, has been demonstrated as having a medium range effect for overall cognitive functioning on six of the seven cognitive domains studied by McGurk, Twamley, Sitzer, McHugo, and Mueser (2007). For example, positive learning experiences bolster self-esteem and self-efficacy for achieving positive goals and improving depression (McGurk et al. 2007). Cognitive therapy is effective. After reviewing 39 studies on interventions that improve medication adherence in schizophrenia, Zygmunt, Olfson, Boyer, and Mechanic (2002) concluded that interventions and family therapy programs that utilize concrete problem solving and motivational techniques are common features of successful programs: "interventions based on principles of motivational interviewing are promising". In a meta-analysis of the efficacy of psychological therapy in schizophrenia, social skills training, cognitive remediation, psycho-educational coping-oriented interventions with families and relatives, as well as cognitive behavioural therapy were found to decrease relapse and hospitalization rates (Pfammatter, Junghan, & Brenner, 2006). There are many types of cognitive-based therapies, and while acknowledging there are significant differences in their approaches, cognitive restructuring is part of the focus. The term "cognitive therapy" will be used to generalize these therapy approaches. This will be discussed further under the implications for practice later in this chapter.

The outcomes of cognitive therapy benefit both acute and community mental health expenditures. Allocation of these resources must not come at the expense of other programs, but rather as a result of restructuring for efficiency. Over the long term, recovery and stability could reduce the expenses generated by mental health clients within hospitals, prisons, and the community. Dr Richard D. Krugman (2008, January), referred to what he called the "Tyranny of Or". This relates to budget provisions for one program *or* the other, prevention programs *or* long-term programs but not both. Mental health managers, often are caught up in this tyranny of choosing between one *or* the other, need to tackle solutions on both ends of the spectrum, from prevention *to* long-term care, not prevention *or* long-term care. At the same time, group cognitive therapy is a cost-effective therapeutic approach (Bieling, McCabe, & Martin, 2006).

16.2.2 Long-term Support

In Chapter Twelve, the efficacy of the therapeutic alliance with respect to recovery and reconstruction of dangerousness was discussed. Several reviews of clinical trial literature conclude that treatment for people with a schizophrenic disorder needs to include three components: optimal dose antipsychotics, psycho-education for patients and caregivers, and assertive outreach management (Malm & Eberhard, 2007). The minimal time for evaluation and modification of treatment is a five-year period; however, very few psychiatric programs evaluate the benefits and risk of treatment beyond one year (Malm & Eberhard, 2007).

Evidence-based practice has shown us that long-term case management is effective and that continuation of care over the lifetime of the person has great potential for saving money (Malm & Eberhard, 2007). Schizophrenia is recognized as a chronic disorder. Hence, there is a shift in medical care from cure to disease management (Fenton, 2003). The therapeutic alliance must be maintained throughout the lifetime in order to sustain recovery of the person in addition to maintaining a link with consumers for quality assurance and evaluation of mental health services. Schizophrenia is an expensive disease, but by moving resources to evidence-based treatment that includes long-term support, there is a "large potential to saving money on 'indirect costs' and on costs for hospitalization and sheltered living" (Malm & Eberhard, 2007). Findings from this study suggest that long-term case management is essential. People with schizophrenia have limited relationships (Goldberg, Green-Paden, Lehman, & Gold, 2001) and rely on the ongoing interaction with their case manager:

> Making connections is not an easy task for someone who has experienced failures, who may be struggling to manage symptoms, and who may not have a good repertoire of social skills. (Farone, 2006, p. 33)

This lack of connection to others can create dependence on professional staff. This "dependence" may be borne from the illness, interfering with normal social development that promotes work, family, and recreation.

People with schizophrenia may lack the social skills necessary to build relationships until they are well into the *Period of Wisdom*. Even then, many in this study stated that their friends were largely peers, also with the illness. They had limited relationships: family members such as siblings and children may have "written them off" long ago, their aged parents may have been deceased, or they did not have the protective factor of marriage (Haro et al., 2006). Furthermore, they had no or few

work-mates, limited funds to engage in recreational activities, and for the most part, remained solitary. Intensive engagement in care may be more important after multiple disappointing relapses and those who have had such relapses in the past, may require ongoing assistance (Prince, 2007). A visit from a case manager may be the only meaningful interaction the person has in a week or a month. If it is this visit that supports them to continuously reconstruct dangerousness and provides them with clinical supervision and reinforcing positive feedback, then we provoke illness when, due to lack of resources, we deny them this support once they are functioning well. Morally and ethically, policy and practice need to work in tandem to provide the environmental linkage to support recovery:

> Full actualization and recovery can only take place with supportive social relationships, circumstances, and opportunities. Recovery relies on an environment … for new or resumed social roles, engagement in relationships with others and meaningful integration in the larger society. Efforts toward integration are performed by the individual and by those in relationship with the individual. (Onken et al., 2007, p. 17)

Recovery cannot and does not happen in isolation. Recovery is not merely an individualistic responsibility (organic) but must come in tandem with a communal response (ecological) and responsibility to support the individual with schizophrenia to recovery over his or her lifetime. This must continue until they have achieved the ability to live among and interact with others in mutual, positive *interdependence,* a hallmark of community inclusion and standard of recovery (Onken et al., 2007). In his welcoming remarks at the 4th International Conference on Social Work in Health and Mental Health, Dumont (2007) said:

> In this view, species having a greater talent for mutual assistance enjoy a significant advantage in ensuring their own preservation and development … mutual assistance can thus be viewed as a natural resource that is always potentially present, but that is translated into action to the extent that a number of other conditions are present or not. This point indeed represents the foundation from which the profession of social work derives all its meaning …

> to this end, we mobilize the most dynamic elements of individuals, groups and communities — something we achieve through actualizing their potential for mutual assistance. Indeed, it is by building and strengthening solidarity that we acquire the capacity to establish compassionate social relationship. (p. 13)

Good practice is maintaining formal interdependence until the *person with the illness deems* they have developed sufficient informal supports for him or herself to disengage or withdraw from formal support. This "deeming" to have support requires sufficient insight to make that type of decision, and it must come in conjunction with a professional decision to stop or continue support. In his above speech, Dumont (2007) quotes Rinpoche's thoughts on sustained support:

> It is not simply a sense of sympathy or caring for the person suffering, nor simply a warmth of heart toward the person before you, or a sharp clarity of recognition of their needs, it is also a sustained and practical determination to do whatever is possible and necessary to help alleviate their suffering. (pp. 14-15)

Social workers hold that endings or termination have always been a part of the social work problem solving process, and, ideally, a social worker attends to the ending of an intervention right from the assessment phase (Walsh & Meyersohn, 2001). However, removal of long-term supports in the face of a chronic illness appears counterproductive. Despite the difficulty in engaging the person with schizophrenia initially, and the cognitive deficits that limit regulation of interpersonal boundary development, Walsh and Meyersohn (2001) continue to support termination though recommend it be handled delicately. Evidence from the current study on insight development is suggestive that intervention, albeit minimal, may need to be carried out over the lifetime of the person due to the chronicity of their illness. Future evidence-based study is necessary to compare outcomes between clients whose support has ended versus those with long-term support.

Ideologically and fiscally, community mental health policy makers must embrace the growing research demonstrating the efficacy of long-term, perhaps, lifetime support, thus ensuring and maintaining the individual's clinical and social support from the worker. Chronic illness does not go away, and long-term case management support can continue to assist with reconstruction of dangerousness and to mitigate deconstruction of dangerousness. Mental health budgets must allocate resources to community case management as a way of not only committing to the health and welfare of the mentally ill but also to being fiscally accountable over the long term. Issues of termination and resources are linked to practice implications.

Addressing the policy implications of clarifying the purpose of dangerousness legislation, along with greater resource allocation for cognitive therapy and long-term support should be primary concerns for policy writers and budget planners. While resource concerns are always paramount, the efficacy of theoretical models needs to be evaluated as a measured outcome. From these evaluations, models can be derived to guide practice. This next section will discuss the implications for practice derived from this study.

16.3 Implications for Direct Practice

Research brings with it implications for practice. This section discusses relevant implications for practice arising from the findings. Specifically, the implications revolve around behaviour change interventions, such as motivational interviewing, cognitive therapy, group therapy, psycho-education, spirituality, and dual diagnosis. The importance of the therapeutic alliance has been discussed in Chapter Twelve. However, the way in which this therapeutic alliance can be applied most beneficially

is not only through case management but also via cognitive therapy and motivational interviewing within the context of individual and group work, and dual diagnosis in both acute and community settings. This also provides an opportunity for developing the identified need for peer support. This section concludes with a discussion of the implications of the importance of spirituality for practice.

16.3.1 Behaviour Change

Mueser et al. (2006) found that development of the Illness Management and Recovery (IMR) program helped clients with schizophrenia or major mood disorders learn how to manage their illnesses more effectively in the context of pursuing their personal goals. The IMR program uses two theoretical models to direct treatment: the *transtheoretical model* and the *stress-vulnerability model* (which was described briefly in Chapter Two). Globally, the Transtheoretical Model (TTM) of behaviour change has been a prominent theory directing substance abuse treatment (DiClemente & Prochaska, 1998). This model has generalizability to other chronic illnesses including schizophrenia. The TTM proposes that motivation to change develops over a series of stages (precontemplation, contemplation, preparation, action, and maintenance). However, Callaghan, Taylor, and Cunningham (2007) challenge the stage movement of the TTM model, at least in addiction recovery. They contend that TTM is overly hierarchical and based too exclusively upon stage-based interventions designed to facilitate a preconception of stage progression. The findings from their study suggest that behaviour improvement can occur even in the pre-action stages of the process, thus showing results "running counter to the model's core predictions" (p. 1593). While these findings are recent and have not yet been replicated, nor are they specific to schizophrenia, it is theoretically possible that motivational interviewing

techniques can "move up the bottom" of what a person thinks is dangerousness to them, and, thus, move people from one stage to the other more quickly, or, may assist a change in thinking prior to any visible action on their part. Motivational interviewing is a tool used to help clients develop their own vision of recovery and to move them through the stages of IMR and TTM to achieve this vision (Mueser et al., 2006).

16.3.2 Motivational Interviewing

Motivational interviewing (MI) is defined as "a directive, client-centred counselling style for eliciting behaviour change by helping clients to explore and resolve ambivalence" (Rollnick & Miller, 1995, p. 326). Motivation is considered as part of a state of readiness for change rather than a personality trait intrinsic to the individual (Britt, Blampied, & Hudson, 2003).

This conceptualization of motivation incorporates a six-stage change structure (Prochaska & DiClemente, 1982). This model of change theorizes that there are six stages of change for the substance abuser: precontemplation, contemplation, determination, action, maintenance, and relapse. Parallels exist between the substance abusers' precontemplative stage of change and persons with schizophrenia's lack of insight. For example, the individuals in the precontemplative stage of change are "either unaware or ignorant" of their problem and are often resistant, defensive, and uncommitted to suggestions or attempts to assist them (p. 13). In addition, they often feel pressured or coerced into treatment. This seems to parallel the findings in this study relating to the *Period of Chaos*.

In the contemplative stage, the individual begins to think about changing his or her behaviour, but may not have yet engaged in actual behaviour changes. The contemplator is characterized as someone who recognizes the existence of a problem, is trying to make sense of it, and is feeling some distress over problem recognition. He or she seeks mastery over the problem. People at this stage of change are disturbed by their ambivalence, aware that they need to change but are unwilling to initiate it.

Miller and Rollnick (1991) explore this ambivalence during the precontemplative and contemplative stages of change and observe how the therapist creates cognitive dissonance in the patient. Cognitive dissonance creates discrepancy and causes discomfort in the perceptual framework of the patient (Festinger, 1957). This discomfort in turn triggers the natural tendency toward resolving dissonance, thus provoking change (Gerber & Basham, 1999).

The spirit of MI is one of curiosity, which elicits motivation to change from within the client and stresses that it is the client's and not the therapist's job to resolve ambivalence. The method warns that direct persuasion is not effective for resolving ambivalence and instead encourages a counselling style that is a "quiet and eliciting", whilst the therapist is instrumental in assisting the patient to resolve the ambivalence (p. 326). Readiness for change is a fluctuating entity of interpersonal interaction rather than a character trait.

Initially developed as a way to motivate people to prepare for the action stage in alcohol abuse, the model is attracting growing interest from other fields, such as diabetes treatment and mental illness treatment (Britt et al., 2003). In a literature

review of the efficacy of MI, Britt et al. found overwhelming evidence of the efficacy of MI for reducing alcohol consumption. They also found evidence that MI can be successful for reducing substance abuse such as heroin, cocaine, and marijuana, as well as for mentally ill dual diagnosis clients. Britt et al. hypothesize that MI may be of particular use for patients dually diagnosed with substance abuse and schizophrenia. Dual diagnosis patients are less likely to benefit from more confrontational approaches used in other substance abuse treatment protocols (Bellack & DiClemente, 1999; Carey, 1996).

Some empirical evidence exists that MI can effectively increase the insight and treatment compliance of schizophrenic patients. In a randomized controlled trial using compliance therapy very similar to MI, and in a clinical trial using MI, both studies concluded that MI was an effective therapeutic approach for improving insight for people with schizophrenia (Rusch & Corrigan, 2002; Swanson, Pantalon, & Cohen, 1999). “MI can, with certain modifications, overcome obstacles specific to schizophrenia such as cognitive deficits, negative symptoms with associated motivational problems and the psychological coping mechanism of denying one’s illness” (Swanson et al., 1999, p. 29). Further empirical research into MI is recommended to determine the efficacy of MI for other health problems (Moyers & Rollnick, 2002) and also for standardization of outcome measures in the evaluation of MI (Madson & Campbell, 2006).

Motivational interviewing (MI) provides at least short-term effects on the motivation of community psychiatric patients and improvement in their attitude to care (Humfress et al., 2002). Despite needing some methodological improvements, there is

promise that motivational interviewing is effective in improving insight in those suffering from mental illnesses and substance abuse (Martino, Carroll, O'Malley, & Rounsaville, 2000). Further, MI shows promise as a useful tool to break ambivalence between denial and recovery. However, cognitive therapy also holds promise.

16.3.3 Individual Cognitive Therapy

There are many types of cognitive therapies. For the purpose of this discussion, cognitive therapy is any therapy designed to modify self-defeating, irrational, or negative beliefs and produce more desirable consequences (Lakeman, 2006). Cognitive Behavioural Therapy's (CBT) central premise is that a person's beliefs, images, inferences, and evaluations mediate their response to the event (Chadwick, Birchwood, & Trower, 1996; Nelson, 1997). Three meta-analyses have been conducted around the use of CBT for persons with psychotic disorders and have confirmed the benefits with this population. However, debate continues regarding the strength and endurance of the results (Glynn, 2006).

Although Sullivan's contribution on object relations and psychosis was made more than fifty years ago, he expanded the understanding of the unique experiences of people with schizophrenia. His ideas include a recommendation for social workers relating to threat (events) (Yip, 2002). Yip (2002) also cites Sullivan's recommendation that, "Social workers should try their best to help the clients to face or even alleviate their environmental stress and external threats" (pp. 245-263). Facing these threats, means, seeing them for what they are: grave physical danger to self or others, serious threats to spoiling relationships with others, significant deterioration of function, and further loss of self. Spotlighting these threats and

keeping the spotlight on the risks or threats may be a method of breaking the ambivalence and denial. Patients often do not see themselves on any road to recovery, rather they have "no coherent view of what had happened, was happening and would happen" (Kinderman et al., 2006, p. 1909). Therefore, professional staff and family will do well to use cognitive therapies to shed light, magnify, and break any ambivalence about the seriousness of the threat to self or others that another event might provoke.

Cognitive therapy can serve two functions: spotlighting the dangerousness of relapsing and also diffusing the belief that their voices are all knowing and all powerful (Birchwood & Chadwick, 1995), thus reducing their response to dangerous command hallucinations. Individuals construct dangerousness for different reasons; understanding what the unique dangerousness is for the person and capitalizing on their strengths can build capacity for change.

Cognitive therapy is an effective means of challenging cognitive distortion, supporting strengths, and providing opportunities for needed peer support. Rollinson et al. (2007) found that therapists working in routine clinical settings were able to establish solid therapeutic relationships with people with psychosis and were able to work on assessing and coping with their psychotic symptoms. They admit there are challenges, however, and cognitive therapy may require some modifications to customize fit between symptoms and therapeutic approaches. Case studies suggesting the efficacy of combined treatment modalities exist, such as that of a treatment resistant man with active religious delusions who improved with cognitive therapy that integrated Jungian and self-psychological perspectives (Silverstein, 2007). This

treatment perspective "started where the client was" and engaged the man in discussion about the benefits and pitfalls of being delusional, which assisted him to identify realistic interests. Initially, social work practice can focus on patients in the community who are stable, but we must endeavour to adapt psychotherapeutic treatment for those who are more acutely ill and have a need for psychotherapeutic assistance (Lakeman, 2006) to promote cognitive change. A study by Rollinson et al. (2007) found that CBT for psychosis, in routine clinical settings, tends to focus more on assessment of symptoms than relapse prevention. Therefore, practice guidelines for cognitive therapy in schizophrenia need to include constructing case formulations and directions on how to intervene with delusions and hallucinations, thought interface, passivity phenomena, and formal thought disorder (Kingdon & Turkington, 2005).

Links between impaired affective interpretations and inability to display empathy and apprehend others' perspectives exist, and these findings must be taken into consideration in therapeutic settings (Shamay-Tsoory et al., 2007). This lack of capacity for affective attunement is beautifully articulated by Chadwick (2007), a psychologist and researcher in the area of psychosis, who provides an autobiographical account of his own experiences with psychosis and social awkwardness:

> The poor context processing affected my social life dramatically; I was forever making remarks and behaving in a way that would slightly alienate people. This is because I would have to grasp situations by apprehending their parts rather than grasping them intuitively and holistically … I would alternate between … callousness … and sentimentality … I could recognize these attentional and integrational problems at least on reflection … felt ashamed and guilty of the 'faux pas' and peccadilloes they created, but also felt totally powerless to change them in real-time behaviour. (p. 167)

Cognitive therapy provides an opportunity to build self-esteem, focus on strengths, construct and reconstruct dangerousness, and utilize peer support in a group setting. Morrison (2008) recommends all patients with psychosis be offered access to cognitive behavioural therapy. Lysaker, Buck, and Roe (2007) are currently developing steps to standardize and measure feasibility, fidelity and effectiveness of psychotherapy in psychosis, thus providing supports to guide practice. Cognitive therapy can also be conducted in group therapy formats.

16.3.4 Psycho-education

The findings present implications for practice in the form of psycho-educational opportunities that can occur in both individual and group formats. Psycho-education approaches are useful and inexpensive treatment approaches for people with schizophrenia (Pekkalla & Merinder, 2002). Psycho-education is an avenue that can increase patients' awareness of their illness and its treatment. In addition, psycho-education can lead to reduced hospitalization rates and mental health costs in schizophrenia (Rummel-Kluge, Pitschel-Walz, Bauml, & Kissling, 2006). Strikingly, cognitive therapy offers an opportunity to reveal the process of insight development and recovery to patients, thus potentially eliminating or mitigating their sense of aimless drifting. It enables their experiences to be constructed as markers on the road map to recovery, or notches on a measuring stick, showing how far they have come and the direction in which they yet need to move. Through psycho-education, people with the illness can learn about the three stages of insight development: the *Period of Chaos,* the *Dynamic Period* including the C.L.A.R.I.T.Y. properties within that period and the *Period of Wisdom*. Many aspects identified in the *Dynamic Period* of recovery can be useful teaching tools for psycho-education. These include teaching and

coaching around the *Four Types of Insight: Introspective Insight*: learning how to introspect and identify feelings and symptoms; *Interpersonal Insight:* learning how to use the responses of others to judge behaviour and social acceptance of their beliefs, and to seek and utilize feedback from others; *Retrospective Insight*: learning how to look back and how to judge the future based on experiences from the past; and *Strategic Insight:* learning about the tools and skills to manage symptoms.

Psycho-education is also an opportunity for practitioners to assist clients with the illness to recognize, learn, and mitigate the effects of the *Four Phenomena of Influence* on the recovery process. As well, it can be an opportunity to assist people with the illness to understand the importance of medication and, more specifically, the right medication for them. This can empower them to self-advocate for medication trials in order to find the best medication fit for them. Finally, psycho-education is also an opportunity to engender hope as people come to realize and understand that the *Period of Wisdom* can be a possible goal for them.

16.3.5 Group Therapy

Group therapy can use a strengths-based model assisting people to recover their lives by realizing their resiliency, strengths, and potentials (Saleebey, 1996). A social worker is a collaborator with the client whereby "to appreciate the strengths of the individual is to begin to understand the uniqueness of the individual" (p. 7). Lawrence, Bradshaw, and Mairs (2006) conducted a systematic review of the literature on group cognitive behavioural therapy for schizophrenia, and although 168 papers had potential relevance, in the end, only five studies met their inclusion criteria. They conclude that while evidence exists of the efficacy of individual

cognitive therapy, more research is required to investigate the potential of group cognitive behavioural therapy for people with schizophrenia.

However, other literature provides some evidence that cognitive group therapy for this population is efficacious. The relational-developmental benefits of group therapy help to create satisfying interpersonal relationships, but also in a Piagetian schematic sense, provide new foundations of "thoughtful procedures to guide future interpersonal behaviour" (Kurzweil, 2008, p. 23), both of which are elements often missing or robbed by the illness.

Group therapy can help to maintain self-esteem and can influence meaning making. Group therapy contains elements of cognitive behavioural therapy, psycho-education, and peer support. Learning in a group therapy setting happens via a number of pathways, including didactic means employed by the therapist, and advice and feedback from other group members. Psycho-education is the cornerstone of group therapy, but so is experiential, problem-based learning (Bieling et al., 2006). Cognitive therapy in a group setting can challenge beliefs, values, and cognitive distortions that threaten to undermine reconstruction of dangerousness. Sigman and Hassan's (2006) research on long-term group therapy shows that group therapy not only mitigates depression, anxiety, and psychosis but assists in the development of humour, support, and insight. Also, suggestive from their study is that participants increased their maturity and functioning in a group setting. Group therapy can also foster empowerment and self-determination to increase participants' sense of control in their lives (Walsh, 2002). Group therapy, designed to enhance self-concept, minimizes the engulfing effects of the illness and contributes to quality of life

(McCay et al., 2006). Group therapy promotes "universality", the recognition that other people experience very similar problems. This is found to be one of the most beneficial factors of cognitive behavioural group therapy with "voice hearers" (McLeod, Morris, Birchwood, & Dovey, 2007). The study also notes a reduction in frequency of voice hearing and in beliefs about the power of voices and an increase in coping strategies.

Kopelowicz, Liberman, and Zarate (2006) report the efficacy of social skill development in promoting independent living and improved community functioning in people with schizophrenia. They also describe social skills training as principles and techniques that teach people with schizophrenia to communicate their emotions and requests so they are more likely to achieve their goals and meet their needs for affiliative relationships and roles required for independent living. Group therapy offers an avenue to learn and integrate these skills.

Group cognitive therapy enhances the problem solving process and has greater opportunity to demonstrate skills than individual therapy (Bieling et al., 2007). Revheim and Marcopulos (2006) recommend that group leaders assess the severity of clients' cognitive deficits, be cognizant of their prior levels of functioning, and accurately gauge their current phase of recovery in order to modify and adapt treatment. They remind therapists that those with cognitive dysfunction must work harder and longer to accomplish the same goals. In addition, they recommend focusing on client strengths and limitations and offering positive encouragement. Implementation of their recommendations may be essential to provide appropriate treatment to help ward off hopelessness in both therapist and client.

Some people with active delusions have been found to have no insight until the interview perspective shifts from a first person focus to a third person focus, thus suggesting that thinking about their own thinking may be impaired (Gambini et al., 2004). Hearing a third person share their story in a group format may be a step to insight development. Also, as demonstrated in the narrative analysis of my research, many participants shared their stories in the third person and this voice may assist in helping with insight development in a group format.

Compelling arguments for the potential efficacy of group therapy comes from Irvin Yalom's (1975) curative factors derived from group therapy. Yalom's book, *The Theory and Practice of Group Therapy*, has become the standard text for group therapy work. In his book, Yalom lists eleven curative factors that are derived from a group process: instillation of hope, universality, imparting of information, altruism, the corrective recapitulation of the primary family group, development of socializing techniques, imitative behaviour, interpersonal learning, group cohesiveness, catharsis, and existential factors. Yalom's curative factors are closely aligned with the essential factors in recovery processes: hope, knowing you are not alone, socialization, education, interpersonal relationships, practice and insight. Group therapy can be a powerful tool to invoke change, develop insight, and promote recovery. Evidence exists that group therapy is beneficial for people with schizophrenia and includes the opportunity for peer support.

16.3.6 Peer Support

Another important component of group therapy is peer support. A peer is defined as "an individual who shares common characteristics with the 'targeted' group or individual, allowing her/him to relate to, and empathize with, that individual on a level that a non-peer would not be able to" (Doull, O'Conner, Robinson, Tugwell, & Wells, 2008, p. 1). Peer support within a health care setting is defined as, "the provision of emotional appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population" (Dennis, 2003, p. 329). Peers participating in these therapy groups are perceived to be people who understand and will not judge, thus removing some of the barriers that potentially can influence self-esteem as they have "personal knowledge of coping with psychiatric disabilities and attendant stigma in society and have a special ability to engage clients and support them in their own recovery" (Rowe et al., 2007, p. 956). People in this study deemed peer support important, and this may have been a more easily fostered first step toward interdependence in relationship. Within the concept of peer support there is a sense of being accepted and understood (Farone, 2006). Peer-counsellors are able to answer questions more adequately, and patients feel better understood and able to obtain support and encouragement (Rummel-Kluge, Stiegler-Kotzor, & Schwarz, 2008). Peer counselling is a potentially useful tool for people with schizophrenia. McPhee (2007), who as noted earlier, is the founder of the Schizophrenia Digest and a person with schizophrenia, recommends peer support groups. One of the participants in my research, Art, provided a profound example of the power of peer support:

> I remember I was on the bus one day and this … 25-year-old East Indian man, and he was experiencing paranoia, and some young kids … came at him, picking on him and annoying him. I put a stop to it and walked with him and

> told him I was schizophrenic too. And he just relaxed. … We are each other's eyes and ears.

Peer support provides safety, comfort, understanding, boundaries, and alleviates the sense of aloneness; these interactional and relational elements are a normal part of healthy socialization. Peer support needs promotion in order to assist persons in the group to assist peers with reconstruction and mitigate deconstruction of dangerousness meaning making. Bracke, Christiaens, and Verhaeghe (2008) reaffirm the importance of peer support groups for people with mental illness, stressing that they not only provide an avenue for gaining personal support but also provide persons with mental illness experiences with an opportunity to provide such assistance. Involvement in providing support leads to self-efficacy and self-esteem:

> Services must nurture peer-support groups not only because they form a welcome resource clients can turn to in a time of need or a reference group for their interpretation and redefinition of their experiences, but more crucially because these groups provide opportunities to support others and hence to enhance feeling self-worth and feelings of competence. (Bracke et al., 2008, p. 453)

Researchers have neglected to study peer support amongst naturally occurring clients of mental health services, and, in particular, naturally occurring peer support groups (Bracke et al., 2008). Group and peer support may be enhanced by the utilization of technological possibilities via such innovations as internet-chat after care groups (Haug, Sedway, & Kordy, 2008). In recognition of its increasingly central place and potential, the National Association of Social Workers in the United States is beginning to address the use of technology in social work practice (Parker-Oliver & Demiris, 2006). Whilst neglected over recent times in favour of more individualistic approaches, agency managers and faculty of social work need to promote the recognition of both "group work and community development approaches as valid tools in the social work repertoire" (Ferguson & Lavelette, 2004, p. 310). The

application of the *Theory of Dangerousness* requires awareness of the continuum of contexts in which recovery takes place, thus countering the dichotomy of "casework vs. community" (p. 310) debates. This theoretical "thread" can guide practice within and around hospital and community, and could help to encourage more seamless service provision. In addition, if we are to respect and learn from the various collective user movements and the mental health consumers, we, as social workers and medical practitioners, need to begin to apply the information provided by people with the illness that is gathered in qualitative research. The collective voices of consumers, expressed via lobby groups and participation in research such as this, supports initiatives to achieve earlier, more sustained recovery via the use of cognitive therapy, MI, group therapy, psycho-education, and peer support.

16.3.7 Spirituality

As discussed in Chapter Thirteen, spirituality was an important support for people in the study. Literature relating to the importance of spirituality and the ongoing debate around spirituality and practice was discussed earlier, in Chapter Thirteen. Most participants used the term "God" to refer to their spiritual deity, but in this discussion I use the more encompassing term "spirituality".

Spirituality appears to be important to many people with mental illness (Weisman, Duarte, Koneru, & Wasserman, 2006). Cornah's (2006) review of the literature found that, overall, there is a general consensus of "cautious optimism about the role spirituality can play in promoting and maintaining good mental health" (p. 32). Spirituality is not ignored when working with indigenous cultures and/or in grief and loss work, yet, in more mainstream practice, social workers tend to avoid this

dimension. Dealing with spirituality is considered to be a legitimate part of culturally sensitive practice, yet we sometimes forget or ignore that Anglo-Saxon cultures have spiritual and religious foundations, too. Carroll (1998) provides a helpful distinction between spirituality and religion:

> Spirituality refers to one's basic nature and the process of finding meaning and purpose, whereas religion involves a set of organized, institutionalized beliefs and social functions as a means of spiritual expression and experience. (p. 2)

Simmons' (1998) definition of spirituality may be a closer fit in the context of this study:

> When people bear responsibility, live as they would like to live, combat the temptation to inner despair or keep chaos from invading the centre, this is the stuff of spirituality. (p. 73)

This distinction assists social workers to consider whether there is a pervasive, even "innate", human propensity to seek a relationship with a deity, and whether this may assist at least some with finding meaning and purpose. In this study, the demographics questionnaire asked about religious affiliation in order to assist the researcher to identify an aspect of cultural diversity. The concept of spirituality or God, however, did not emerge as a result of questions asked in the study. Instead, participants brought forth the concept when exploring their sources of support. Their discussion evinced that a relationship with God, as they referred to their spiritual being, was significant and powerful in their lives as people with schizophrenia. Mohr et al. (2006) hold that spirituality needs to be integrated into the psychosocial dimension of care since the benefits of faith and spirituality include increased coping skills, greater social supports, greater resilience to stress, as well as greater optimism, and relaxation in response (Miller & McCormack, 2006). Miller and McCormack propose that assessment include a patient's religion to facilitate referrals and the provision of appropriate help when a crisis occurs. This might involve facilitating contact with a

chaplain or church members, or simply encouraging the person to attend their church or to pray in their home. Due to the complexity of the dynamics between religion and schizophrenia, practice must take a highly sensitive approach to the uniqueness of each story (Mohr et al., 2006).

Dr Andre Gagnon, in his speech at the 3rd International Conference on Spirituality and Mental Health in Ottawa, Canada, reports that patients appreciate specific attention to what is at the "very intimate core of one's self" (as cited in Hodges, 2007, p. 32). Clinical social workers have always "attended" and paid attention to the core values and beliefs of their clients by being open, accepting, and non-judgemental (Cournoyer, 1991), and their spirituality may be a core value and belief that needs attending to. According to Holloway (2007), there is less sympathy toward spiritual practice in the social work profession in the United Kingdom than in the United States and Canada, particularly from social work educators. Even when practitioners identify spirituality as an issue for clients, Holloway believes they are uncomfortable due to the lack of theorizing and practice guidance in the area. This may be due, in part, to the fact that spirituality literature tends to operationalize spirituality solely in Judeo-Christian terms which can lead to biases and assumptions that can be offensive (Cornah, 2006). An emerging group of researchers is exploring ways to measure the "so-called non-empirical dimension of spirituality" (Holloway, 2007, p. 32). Weisman et al. (2006) recommend that religious, spiritual, and philosophical coping mechanisms be built into culturally-informed, family-focused treatment for schizophrenia.

The rise in spirituality in social work is a counterforce to individualism and the overweening emphasis on the need for empiricism, and finds expression in appeals for an "ecospiritual social work" that takes social work back to its communitarian roots (Gray, 2008, pp. 175-196). Rennebohm, a United Church of Christ minister in Seattle, Washington, makes suggestions to practitioners on how to "bridge the gap" (as cited in Morra, 2008, p. 23) between matters of biology and matters of the spirit. He recommends we sort out what are matters "of illness" and what are matters "of the spirit" (p. 23), explore and blend both the spiritual and neurobiological dimensions of the illness, thereby assisting persons with the illness to find new meaning and direction for their lives.

When social work practitioners identify a spiritual need as an issue for their clients, it is not so much the ideological differences around religion and spirituality that pose a problem for them, but rather concern over "inadequate theorizing and lack of practice guidance" (Holloway, 2007, p. 265) that leads to the continuing inhibition and resistance to working with patients and their spiritual beliefs.

In the United States, steps have been taken by educators in social work, psychology, and psychiatry to address questions of cultural and religious diversity concerns within curricula (Weaver & Samford, 1998). While levels of religious belief and behaviours vary from country to country (Williams & Sternthal, 2007), further academic scholarship needs to develop theory and practice guidance around supporting people's relationship with their God. Theoretically-based practice guidelines may allow practitioners greater comfort in delving into this very personal but meaningful support system of clients.

The spiritual component may also be significantly important to those with dual diagnosis who use the Alcoholics Anonymous model for recovery from addiction. Recovery often begins after an event that involved substance abuse. Dual diagnosis intervention may include taking an important opportunity to assist the person with the illness toward meaning making of the dangerousness of an event. A full discussion of the implications of a dual diagnosis is beyond the scope of this paper but remains an important precipitator of the negative events within the *Trinity of Crisis* as a factor that appears to provoke recovery.

Many practice implications arise from the research findings. If meaning making of dangerousness is what promotes recovery, then practice models need to shift more toward cognitive therapy, MI, and group therapy where both professionals and peers can influence that meaning making. In addition, practice with dual diagnosis clients needs to incorporate awareness that turning points may be associated with the event due to the meaning making of dangerousness following an event that occurs in conjunction with the substance use. Practice guidelines need to address competent social work practice around spiritual issues.

Research and practice do not exist in isolation from policy making but stand in reciprocal and cyclical relationship to one another. Policy directs practice, but then practice information and outcome measures derived from research provide policy makers with new information to guide them, and thus the cycle continues.

Research often provokes more questions than answers, and from this research study, additional questions arose that need further investigation. Outlined in the next section are the recommendations for further research.

16.4 Future Research

This study has highlighted and additionally provoked the need for greater exploration and understanding of the development of insight for those with the mental illness of schizophrenia. This section outlines these directions for further research.

16.4.1 Cognitive Research

There is growing evidence to support that "self constructs", such as self-efficacy, self-esteem, and social ability, facilitate coping. As esteem appears to need to be intact to facilitate reconstruction and prevent deconstruction, how can this be preserved and developed? What is the effect of cognitive therapy, motivational interviewing, group therapies, and peer support when focusing on the perception of dangerousness? In addition, there is a need to explore the place of experiential learning versus learning from the mistakes of others in insight development and how the relationship between cognitive deficits and the number of cycles of relapse and recovery correlate. Fully exploring through further cognitive research how to evoke a *Butterfly Effect* (a small cognitive change in the meaning making of dangerousness after an event) seems worthwhile.

16.4.2 Replication of the Study

Qualitative studies cannot be precisely replicated; however, further qualitative investigations along similar lines in more diverse contexts are warranted. In addition, quantitative studies may assist in validating, refuting, or evolving some of the findings. Including additional variables into replication studies might also expand our understanding..

While diversity in sampling was welcomed during recruitment, aboriginal or visible minority people were not referred for the study. This may be due, in part, to a lack of active recruitment for diverse participants. Conventional mental health professionals were approached for and may not have had access to aboriginal or diverse clients. Additionally, the criteria for participation may have been too exclusive to expect referrals from diverse participants. The criteria included: referral by a mental health professional, stable insight, substantial professional support and the absence of a dual diagnosis.

Being an exploratory study, the researcher took care to avoid extraneous variables potentially confounding the findings but repeat research on this topic of insight can address this research sampling gap. Four aspects of cultural sensitivity need consideration when designing subsequent research. Firstly, it is important for the researcher to seek cultural consultation from aboriginal and/or visible minority groups to assist in recruitment and setting out criteria that can both meet the aims and objectives of the research whilst being sufficiently inclusive to include a diverse sample. Secondly, this consultation is helpful in assessing if the semi-structured interview questions are culturally sensitive and sufficient to access the rich data required for the study. Thirdly, the consultant can assist with ethical considerations of

informed consent that may be unique to diverse cultures. Fourthly, the consultation person can assist in the final analysis and interpretation of the findings. Repeating the research to include a diversity component is necessary for comparisons of cultural differences and/or similarities.

This research interviewed a cross section of people who support people with schizophrenia (psychiatrists, occupational therapist, nurse, life skills worker and a family member). However, further study needs to include a greater contingent of family members as recovery competency requires family perspectives and family participation. Their participation may assist with a greater understanding of the role the family plays in insight development and to further validate or refute the findings of the research.

Within the Canadian and international context, the impact of Early Intervention (EI) training and support on insight development may impact the ongoing relevance of aspects of the study. Therefore, undertaking a similar study with a group of participants who have had Early Intervention (EI) support is warranted.

16.4.3 Further Exploration of Study Concepts

Replication of the study can determine if the *Theory of Dangerousness* can determine if all theoretical concepts are explained and are practical, dynamic, and simple (Polansky, 1986). These theoretical concepts, gathered under the rubric of the *Theory of Dangerousness*, include: the *Paradox of Insight,* the *Process of Insight Development* (the *Period of Chaos,* the *Trinity of Crisis,* the *Dynamic Period (C.L.A.R.I.T.Y.),* and the *Period of Wisdom*), as well as the *Four Types of Insight,* the

Four Phenomena of Influence, and the *Four Constructions of Dangerousness.* These seem critical to explore more fully as it is within these constructions that the cognitive change that drives behaviour takes place. Why do people *preconstruct* dangerousness after an event? How, exactly, does *construction* take place? What factors are involved in *reconstructing* dangerousness? What, exactly, causes or leads to *deconstruction?*

In addition, the concept of the *motivational factor* (*mf*) that moves people from one stage of change to another needs further investigation, and it might also be useful to explore the role of family in dangerousness meaning making.

16.4.4 Spirituality

Since this study did not set out to investigate spirituality, a more focused study might usefully explore such issues as to how people with schizophrenia balance non-delusional spirituality and delusional thinking. The importance of spirituality in the lives of people with schizophrenia clearly needs further investigation and closer attention to the implications of this for practice might culminate in outcomes such as practice guidelines for working in the spiritual realm with people with mental illness.

16.4.5 Scales, Personality and Experience

This study gave rise to a new conceptualization of dangerousness. Qualitative and quantitative input is required for the development of insight scales around dangerousness in order to measure baselines and to determine what constitutes dangerousness for individuals with schizophrenia, whether this change over time, and what interventions influence change. The narrative analysis provoked the question:

What is the relationship between personality traits and recovery? Two final questions remain: What is the relationship between recovery and insight in relation to the maturity and experience of middle-aged person with schizophrenia? What is the efficacy of termination versus long-term support for the chronically mentally ill?

As outlined, further qualitative and quantitative research is necessary to explore, question, verify, validate, and clarify concepts that arose from the study. While the study findings are exciting, there are limitations to the research study and these are addressed in the following section.

16.5 Limitations of the Study

Several limitations of the study exist. Firstly, the study sample is small (n=19) but appropriate to qualitative research as the study reached saturation (no new data) at (n=17). Strong themes emerged quickly and continued consistently throughout the study, but it is possible that a more diverse group of participants may have changed the outcomes of the research study. Sampling was conducted in a small city with a population size of about 90,000 inhabitants, except for (n=1) who lived in a larger Canadian city. It is possible that individuals who met the sampling criteria and had even greater insight development may have moved to larger communities for vocational or educational opportunities.

Although the researcher sought cultural diversity in terms of race and/or sexual preference, no ethnically diverse samples were located or offered for the study. This limitation must be explored in any replication of the study as insight in respect to

culture is important to investigate. In addition, sampling contained only Canadians and, therefore, this study needs replication in other cultures as well.

Due to the time lapse since their first break, people in the study had not been recipients of Early Intervention (EI) strategies. Research findings might change for those who have had EI support. This is an inevitable limitation of the study, as policy and practice changes will occur over the time people with schizophrenia take to develop insight. These changes and a further time delay will also impinge on the results of research yet to be published in scholarly journals. Finally, because the researcher speaks and reads only English, the literature search was limited to English language publications only.

In light of the research findings and the *Paradox of Insight*, that showed participants needed to "learn the hard way", we need to question how we, as society, think about issues of self-determination, incarceration, hospitalization, and therapeutic jurisprudence. Reflecting on the implications for policy and practice from this research may create concern for those interested in the health and welfare of people with mental illness. However, we should not allow our concerns to override the opportunity to reconsider our practices and policies and their implications for the well-being of people with schizophrenia, their families, and their communities who have the potential to take a much greater part in the development of future treatment and intervention programs. The *Theory of Dangerousness* presented in this research, when implemented as a theory to guide intervention, may offer us with efficacious evidence-based outcomes that can reciprocally guide new practice and new policy.

16.6 Conclusion

As behoves a social work thesis, this final chapter has examined the implications of these research findings for policy and practice. It began with a discussion of social work's influence in the cognitive therapy realm and the importance of group therapy, peer support, and motivational interviewing in relationship to dangerousness meaning making. In addition, based on the research, an argument for the importance of long-term support was made. The chapter also discussed the policy implications of the research. As a clear finding in the study was around the importance of issues of spirituality, the implications of this finding were discussed. This research raised many questions and, therefore, the chapter recommended some further research around policy and practice to provide clarification and verification. The chapter concluded with a disclosure of the limitations of the research.

This chapter also concludes the thesis. At the beginning of the thesis, the reason for the interest in the topic of insight for persons with schizophrenia was conceptualized, rationalized, and theorized through a literature review. The rationale for using grounded theory methodology was documented and the research design presented along with the sampling criteria and a description of the sample participants.

Grounded theory analysis and narrative analysis of the research data provided the following theoretical concepts: a *Process of Insight Development* (the *Period of Chaos*, the *Dynamic Period* and the *Period of Wisdom*), a *Paradox of Insight Development*, *Four Types of Insight* and the *Four Phenomena of Influence* that affect the insight process, and the *Theory of Dangerousness* that includes the *Trinity of Crisis*, the *motivational factor (mf),* and the *Four Constructions of Dangerousness*.

The research data also demonstrated the importance of spirituality to persons with schizophrenia; and the implications for policy and practice within spirituality and the theoretical concepts listed above were discussed. Finally, the paper made suggestions for further research around these findings and outlined the limitations of the research.

The concept of insight in schizophrenia and the importance of insight in schizophrenia recovery are well documented. It is possible this research increases our insight into this insight and takes our understanding of schizophrenia one step further.

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APPENDICES

Appendix A

Letter of Introduction

Date:

Hello,

I am a PhD social work student doing research on people with schizophrenia. I am trying to learn more about how a person with schizophrenia comes to know and understand they are sick. The name of my study is: **Insight into Insight: A Study on Understanding in Schizophrenia.** The purpose of this research is to try to determine through personal interviews and focus groups what makes a person know and understand that their symptoms are part of an illness. We believe that if we can better understand how someone develops this understanding we can better assist a person to recover.

Do you meet the following criteria?

1. *Your doctor has told you that you have schizophrenia*
2. *You have been in hospital in the past due to your illness*
3. *You have a good understanding of your illness and/or have not been in hospital in the last two years*
4. *You are not currently using street drugs or alcohol*
5. *You are between 20 and 65 years of age*
6. *You have support from a physician or mental health worker*
7. *Have no cognitive impairment such as brain injury, autism or developmental delay.*

What will happen?

1. I will phone you to set up a time and place that is comfortable for you

2. I will explain why we want you to participate, what will happen in the interview and what is expected of you. Then I will ask you to sign a consent form.
3. I will ask you several questions to help me understand how you know you have an illness.
4. I may ask you if you are willing to meet with other people with schizophrenia to hear what I have learned and see if it makes sense to you. You understand that if you participate, others will know you are taking part in the study.
5. I will use hand written notes and will audiotape our sessions to record the information. The transcript of our interview can be made available to you.
6. The findings of the research will be recorded in a PhD thesis and submitted for publication.

I will collect information on paper that will include: your age, your sex, your education, your country of origin, your religious affiliation, if any, your marital status, what kind of home you live in, your work and if you are a parent. age, gender, education, ethnicity, religious affiliation, marital status, housing and employment. I am interested in how old you were when you were first hospitalized, how long it takes you to get better, how often you have been hospitalized and how long you have been well. I also want to know what medications you are taking and the dosage. If you choose to take part in the focus group, you must understand that others in the focus group will know you have schizophrenia but the information collected on paper will not be viewed by fellow focus group participants. The audio taped interviews will take about one to one and a half hours and if you choose to participate, the focus group will take approximately one hour.

Confidentiality: Your participation in the research is voluntary, and you can stop or withdraw from the study at any time without any consequences. Only I, my supervisors and the person who transcribes the data will have access to your information. The transcribers and all supervisors will sign a confidentiality agreement. I am bound by the Code of Ethics of the Board of Registration for Social Workers of the Province of British Columbia to keep your information confidential and this research has been approved by both the Human Ethics Committee of the University of Canterbury and Interior Health Research Ethics Board.

Your name will never be attached to the interview notes and all real names will be removed before the results of the study are reported in a journal, report or other publication. Audiotapes and notes will be kept in a locked cabinet for no more than five years before I destroy them and electronic information will be locked with a password. Electronic data will be kept for five years and then deleted from the researcher's home computer, work computer and jump drive. Audiotapes and handwritten notes will be given to a confidential document destruction agency for disposal.

Once all the interviews are completed, I will be analyzing the findings and presenting them to a group of mental health professionals to obtain some feedback from them regarding my analysis. To protect your identity, no identifying data will be used.

Risks: It is possible that you will find some of the questions upsetting. Please tell me and we can stop, take a break or end the session altogether. You have the right to withdraw from the research at any time and your decision to not participate in the research will in no way affect your access to treatment or mental health care. If you continue to feel upset, I suggest you get support from your physician or mental health worker.

Your participation is important and I invite you to take part in the study. In order to book an interview and to give you all the information about the study, I request you initiate contact in the following ways: either call me directly or complete the 'consent to contact' form attached to this letter. You can drop it off at the mental health office, RIH switchboard or mail it to me at work (address on the consent to contact form). My phone number is (250) 374-5017 (h) and (250) 314-2251 (w). In the event that I am not in at the time of your call, please leave a number and time I may return your call.

Once contact is made, I will then call you to book an appointment. We can meet in a mutually suitable place where you feel most comfortable.

Contact: If I you have any questions or want more information, I ask you to contact me at the above phone numbers. If you have any concerns about your rights or treatment in this research, I ask you to contact the Chair of the Interior Health Research Ethics Board, 250-870-4649.

Sincerely,

Wendy Nordick
PhD Student
Principal Investigator

Supervision provided by:

Dr Kate van Heugten	Dr Kurt Buller	Dr Elliot Goldner
Senior Lecturer	Head of Clinical Psychiatry	Professor, Simon
University of Canterbury	Royal Inland Hospital	Simon Fraser University

Appendix B

Consent Form

Wendy Nordick
Principal Researcher
University of Canterbury
In conjunction with the Interior Health Authority
311 Columbia St.
Kamloops, BC

Insight into Insight: A Study on Understanding in Schizophrenia

I have read and understood the description of the above named project. On this basis, I agree to participate as a subject in the project, and I consent to publication of the results of the project with the understanding that anonymity will be preserved.

I understand that I may at any time withdraw from the project, including withdrawal of any information I have provided.

I understand that if I wish a copy of the research's Executive Summary and/or a transcription of my interview, I can call the researcher at (250) 374-5017 and a copy will be mailed to my address.

Name (Please print):_____

Address: _____

Phone Number: _____

Signature: _____

Date: _____

I have received a signed copy of this consent form _____

Appendix C

Insight into Insight: A Study on Understanding in Schizophrenia

Questions to Assess Capability to Consent

1. Why am I doing this study?
2. Do you know why I have chosen to speak to you?
3. What will you and I be talking about?
4. Where will we do the interview?
5. Are you ok meeting with others who have schizophrenia?
6. Are you ok if they know you are taking part in the study?
7. Is anyone making you take part in this study?
8. How will I be recording the information?
9. Do you understand how I will keep the information private?
10. What can you do if you decide you don't want to participate in the study at any time?
11. Do you have any questions or concerns?

Appendix D

Sociodemographic Information

For The Study Insight Into Insight: A Study On Understanding In Schizophrenia

- **To be completed, with the researcher, at the time of the interview**
- **This information is confidential. A false name will be used for the study. Your real name will be removed and a code name will be assigned. Only the researcher will have access to the code sheet containing the identifying information. The code sheet will be kept in the home office of the researcher.**

Name:

Birth date:

Male or Female (circle one):

Highest level of education (circle one): 0-7 8-9 10-11 12-13

One year post secondary Two years post secondary Bachelor Degree

Masters Degree PhD

Ethnicity:

Religious Affiliation/Spirituality, if any:

Marital Status (circle one): single married divorced

separated common-law

Housing: (circle one): apartment house room & board

Circle one: Live alone Live with others

Current employment (circle best answer): volunteer part time full time

Do you have a mental health CM (circle one): yes no

Have you ever had a mental health CM (circle one): yes no

How old were you when you were first diagnosed with schizophrenia:

Number of hospitalizations (circle one): 0-5 5-10 10-15 15 or more

Date of last hospitalization:

What medications are you taking and the dosage?

Are you a parent? Yes No

Are there children in your home? Yes No

If yes, please list the age of your children:

If you are a parent, but don't have full custody of your children, how often do you have your children visit in your home?

Appendix E

Semi-structured Interview Questions

Signs and Symptoms

Purpose: to determine what signs and symptoms are triggers to knowing a relapse is pending

1. How and when do you know that you are becoming unwell? What are your first signs?
2. What are your most troubling symptoms and why are they troubling?
3. What thoughts/beliefs/symptoms or experiences do you have that let you know you are unwell? How do you know these thoughts are not based on reality? Do you spot these now?
4. Was there a time when you didn't know you were unwell? Do you remember how you explained the symptoms at the time? Does that differ from your view of the symptoms now? (Examples: odd behaviors, suspiciousness, illogical thoughts)
5. How easy or hard is it to separate the symptoms from who you are?
6. What steps do you take to better manage your symptoms?

Medication

Purpose: to determine how a respondent understands the importance of medication to their illness and recovery

7. Why do you take medication? How did you come to realize that the

medication reduced your symptoms?

8. What do you notice the medication does to your symptoms?
9. Which symptoms does the medication best manage? Are there symptoms that the medications don't manage well?
10. Is there any time that you don't want to take your medication? If so, why?

Insight

Purpose: to try and identify process to insight or variables that contributes to insight

11. Was there a point after your initial diagnosis when you began to understand you had an illness? Where were you? What happened?
12. Did that understanding stay with you or did it sometimes slip away?
13. What helped?
14. What hindered?
15. Are you aware of anything that takes away or diminishes your insight at times?
16. Was there a significant turning point or major event in your illness when you began to take more control over the illness?
17. What has helped you to understand that you are sometimes unwell?
18. How do you define your ability to know when you are unwell?
19. Why do you think that you have been successful in avoiding hospitalization in the past two years or more?
20. What word would you use to describe your ability to understand that your symptoms are related to an illness?
21. Are there some symptoms you know are part of an illness, but cannot admit to others? Why can you not admit them to others?
22. What is your worst fear about your illness?

23. Does this fear contribute to your own management of the illness? How?
24. How do you see the future? What do you plan to do to stay well?

Environment

Purpose: To determine if and how the environment/others contribute to insight development

25. What or who played an important role in your development of insight?
26. Has your family talked to you about being unwell – how you thought or behaved then?
27. Have you ever seen others that have had similar experiences? How did that affect you? Did this help you in any way?
28. Who or what has been the most important factor in your awareness of your illness?
29. Do you view the world differently since you were first diagnosed?
30. Were you diagnosed quickly after symptoms emerged?
31. Do you think it would be better or worse if you had been diagnosed earlier or later?

Intrapersonal

Purpose: to identify if participant has attributes or qualities that contribute to insight

32. What are your strengths?
33. What or who has contributed to your strengths?
34. What do you think are your strengths that allow you to manage your symptoms?
35. Has there been anything positive, or were there any gains from having the symptoms of schizophrenia?
36. Do you think your awareness of knowing when you are ill is a help or a

hindrance to your life as a person living with schizophrenia?

37. How much control do you think you have over your illness? What gives your illness power over you? How do you get your power back?

Conclusion

Purpose: to ensure, at termination of the interview, that the respondent is safely connected with the present and leaves with a sense of efficacy and positive potential about self and the research.

1. What did you hope to gain from taking part in the research?
2. What do you hope the research accomplishes?
3. Do you have any ideas or advice for others?
4. Do you know where you can receive support if you are or become uncomfortable about the questions at some point?

Appendix F

Dear Doctor/ Mental Health Worker

I am a PhD social work student conducting research on people with schizophrenia. My work is entitled: **Insight into Insight: A Study on Understanding in Schizophrenia**

1. You have been identified as a mental health worker who may be working with or know of a person with schizophrenia who meets the following criteria for the study:

    i. *Have a diagnosis of schizophrenia based on DSM-IV criteria*.
    ii. *Several hospital admissions in the past due to psychotic symptoms.*
    iii. *Be identified as having good insight into their illness and have had no hospitalizations in the past two years*.
    iv. *No alcohol or street drug dependence according to the DSM-IV*
    v. *Are between 20 and 65 years of age*.
    vi. *Have no cognitive impairment such as brain injury, autism or mental retardation*

Study Procedures:

1. Telephone contact to set up a mutually agreed upon time and place
2. Informed consent will be fully explained. All participation is voluntary and can be withdrawn at any time. Once all consent criteria are explained, the consent form will be signed
3. One to one and a half hour long interview that will attempt to understand how the person has been able to develop insight into their illness by searching for reasons, factors, concepts, meanings, events, actions, processes or theory to explain this phenomenon and to assist in research design. Data analysis will take place throughout the study procedures.
4. One hour focus group in a mutually agreed upon setting to analyze the research findings. Only those agreeing to participate will attend the focus group.
5. The researcher will use hand written notes and audiotapes to capture the data in the interviews and focus groups. The audiotaped interviews will be transcribed for analysis.
6. Transcription of their interview will be made available to the participant, if desired.

Confidentiality:

Any information resulting from this research study will be kept strictly confidential. I am bound by the Code of Ethics of the British Columbia Board of Registration for Social Workers to keep information confidential and this research has been approved by both the Human Ethics Committee of the University of Canterbury in New Zealand and the Interior Health Authority's Research Ethics Board. All data will be identified only by code number/pseudonym and kept in a locked filing cabinet for five years until destruction. Participants will not be identified by name in any reports of the completed study. Records kept on the computer hard drive will be kept secure with a confidential password. At the end of the five year period, all transcripts, audio tapes and any hand written data will be given to a document destruction agency for disposal. Access to the raw data is limited to me, my supervisors and my transcription assistant, who will all be required to sign a confidentiality agreement.

Those participating in the focus group agree that their confidentiality is limited by the participation of others in the focus group. I will collect information on paper that will not be viewed by fellow focus group participants and that will include: age, gender, education, ethnicity, religious affiliation, marital status, housing and employment. In addition, information on age at first break, length of hospitalizations and number of hospitalizations will be collected along with medication and dosages.

Your participation is important as you are the people who are most likely to be in contact with those who have good insight into their illness. I request that you provide the accompanying letter to any persons that meet the above criteria and encourage their participation in the study. Please request they call me directly, or complete the 'consent to contact' form attached to this letter. It can be dropped off at the mental health office, RIH switchboard or mailed to me at work (address on the consent to contact form). My phone number is (250) 374-5017 (h) and (250) 314-2251 (w). Thank you for your consideration on assisting with this research project.

Sincerely,

Wendy Nordick
PhD Student

Supervision provided by:

Dr Kate van Heugten
Senior Lecturer, University of Canterbury
New Zealand

Dr Kurt Buller
Head of Clinical Psychiatry
Royal Inland Hospital, Kamloops, British Columbia, Canada

Dr Elliot Goldner
Head of Mental Health Evaluation and Consultation Clinic
Simon Fraser University, Vancouver, British Columbia, Canada

Appendix G

Consent to Contact

I, _____, have read the Letter of Introduction regarding the research, Insight into Insight: A Study on Understanding in Schizophrenia and agree to participate.

I can be reached by calling: _____

By email at: _____

Or, by message at: _____

_____ _____
Signature Date

Please mail to:

Royal Inland Hospital
1 South
Wendy Nordick
311 Columbia St.
Kamloops, BC
V2C 2T1

Or email me at: wendy.nordick@interiorhealth.ca

Or fax this form to: Wendy Nordick 314-2359

Or, drop off at: Royal Inland Reception with attention to my name: Wendy Nordick – 1 South or at Mental Health Reception

Appendix H

Interior Health Privacy and Confidential Information Form

Interior Health Administrative Policy Manual Code: Ar Information
Interior Health Authority
AR0400 1 of 8
/hal/AR0400 December 2003

AR0400 - PRIVACY AND MANAGEMENT OF CONFIDENTIAL INFORMATION
DECEMBER 2003

1.0 PURPOSE

To protect the legal rights of our Clients, Staff and Agents to privacy of their personal and business information in our custody and control.
To define Confidential Information and its management in Interior Health.

2.0 DEFINITIONS

See Appendix A.

3.0 POLICY

Interior Health recognizes:

- the rights of our Clients, Staff and Agents to protection of privacy regarding all aspects of their personal and business information, in keeping with the *Freedom of Information and Protection of Privacy Act;* and
- our requirement to inform our Clients, Staff and Agents that there are circumstances that override their right to privacy when personal information will be shared with authorized individuals.

Interior Health expects that Staff and Agents who come in contact with Confidential Information as a result of their appointment/association with Interior Health will:

- access/discuss only that Confidential Information that is needed to carry out their

Client/service responsibilities;

- preserve confidentiality of Confidential Information while engaged in Interior Health work and outside of work;
- follow Interior Health policy/procedure in the security and release of Confidential

Information; and

- report breaches in accessing Confidential Information or maintaining confidentiality**,** without fear of reprisal. Interior Health considers intentional viewing of Confidential Information that is not required to carry out work-related responsibilities or misuse of Confidential Information to be a breach of access rights/confidentiality. Interior Health will initiate action against those who breach access or confidentiality standards, up to and including dismissal, termination of privileges, termination of contractual agreements and/or

legal action. For examples of access/confidentiality breaches, see Appendix B.
A *PRINTED* copy of this policy may not be the most recent version. The *OFFICIAL*
version is located on IHNET at the Policies, & Procedures Home Page.

Prior to commencing their relationship with Interior Health, Staff and Agents will sign a *Privacy and Confidentiality Acknowledgement* form outlining individual responsibility for access to and use of Confidential Information.
Audits will be performed to ensure compliance with this policy.
All projects or initiatives that collect, use or disclose Confidential Information must complete a
Privacy Impact Assessment (PIA) prior to implementation of the project/initiative to identify and address any impacts on privacy that may result.

4.0 PROCEDURE

4.1 Staff and Agents

- Review the *Privacy and Management of Confidential Information* policy/procedure and sign a *Privacy and Confidentiality Information Acknowledgement* form prior to commencing his/her relationship with Interior Health.
- Complete an incident report for and report any breaches in accessing Confidential Information or maintaining confidentiality to a manager/medical administrator or designate, as appropriate, without fear of reprisal.

4.2 Manager/Medical Administration

- Ensure new Staff and Agents sign a *Privacy and Confidentiality Information Acknowledgement* form prior to commencing their relationship with Interior Health.
- For privacy and confidentiality breaches:
- Notify the Coordinator, Information Security if the breach involved Confidential
Electronic Information.
- Investigate and act on reported incidents.

4.3 Human Resources/ Volunteer Services/ Medical Administration/ Purchasing/ Contract
Managers
- File signed Privacy and Confidentiality Information Acknowledgement forms in
personnel/student/other files as indicated.

5.0 REFERENCES

- Canadian Health Records Association (1995). Principles and Guidelines for Access to and Release of Information

• Canadian Medical Association (1998) Health Information Privacy Code
• COACH (1995). Guidelines to Promote the Confidentiality and Security of Automated Health Record Information
• Family and Child Service Act
• Freedom of Information and Protection of Privacy Act
• Hospital Act
• Hospital Insurance Act
• Interior Health (2002) Standards of Conduct for Interior Health Authority Employees
• IH Policy: Security of Information
• IH Policy: Release of Information

APPENDIX A

2.0 DEFINITIONS

Agents are individuals or organizations that have a business relationship with Interior Health and at the discretion of Interior Health are deemed to have the potential to access, intentionally or inadvertently, all forms of Interior Health Confidential Information.

Examples of agents include, but are not limited to, physicians and other privileged Staff, health care providers, researchers, students, contractors, subcontractors, vendors, suppliers, and any individual directly or indirectly associated with Interior Health.

Clients include patients, residents, and customers of Interior Health.

Confidential Information whether oral, written, and electronic or film, includes the following:

a) personal information about Clients, Staff and agents that includes their:
• name, address or telephone number
• race, national or ethnic origin, colour, or religious beliefs or associations
• age, sex, sexual orientation, marital status or family status
• identifying number, symbol, or other particular assigned to them
• fingerprints, blood type or inheritable characteristics
• their health care history, including a physical or mental disability
• information about their educational, financial, criminal or employment history
• personal views or opinions, except if they are about someone else.
• and anyone else’s opinions about themselves.

b) business information collected or created by Interior Health that exists regardless of form and includes, but is not limited to:
• information provided to Interior Health by an external vendor which, if disclosed
would harm the business interests of the external vendor;
• information prepared as part of pending or ongoing litigation, law enforcement
investigation, quality assurance review, Workers' Compensation Board or Ombudsman investigation;
• information related to credentialing, discipline, privilege, quality assurance reviews and external review of quality of care;

• in-camera deliberations of Interior Health where such topics as personnel, labour relations, land acquisitions or litigation may be discussed;
• unpublished statistical information and internal correspondence related to organizational initiatives; and
• information supplied in confidence to a mediator or arbitrator to resolve or investigate
a labor relations dispute.
c) all information that, if disclosed without authorization, could be prejudicial to the interests
of Interior Health and associated individuals or agencies; and
d) organizational business information that would harm Interior Health's financial interests and/or information that relates to the management of Interior Health that has not yet been implemented or made public.

Privacy is a right that prevents the unauthorized collection, use, or disclosure of personal information.

Staff includes individuals employed, privileged, contracted or on a volunteer basis with Interior Health.

APPENDIX B

EXAMPLES OF BREACHES OF PRIVACY AND CONFIDENTIALITY

Examples of breaches of Privacy or confidentiality include, but are not limited to:

Accessing information that you do not need to know to do your job:

• Unauthorized reading of a Client's chart.
• Accessing information on yourself, children, family, friends or co-workers.
• Asking co-workers for information that you do not need to do your job.
• Showing, telling, copying, selling, changing, or disposing of Confidential Information that is not pertinent to your role or care activity.

Providing access to your sign-on code and password for computer systems:

• Telling a co-worker your password so that he or she can log onto a computer system.
• Telling an unauthorized person the access codes for employee files or Client information.
• Leaving your password in plain view so that others may know it.

Providing or gaining unauthorized access to physical locations (e.g. file cabinets), which contain Confidential Information:

• Lending out your keys to someone else to access file cabinets, file storage areas or other areas where Confidential Information is stored, OR using another's keys for the same purpose.
• Leaving file storage areas unlocked when they should be locked.

Leaving a password-protected application unattended while signed on:

• Being away from your desk while you are logged into an application.

• Allowing a co-worker to use your application for which he/she does not have access after you have logged in.

Sharing, copying or changing information without proper authorization:

• Making unauthorized entries or deletions to a Client's chart.

• Making unauthorized changes to an employee file.

• Discussing Confidential Information in a public area such as a waiting room or elevator.

Using another person's sign-on code and password:

• Using a co-worker's password to log onto a computer system.

• Unauthorized use of a login code to access employee files or Client accounts.

• Using a co-worker's application for which you do not have rights after he/she is logged in.

Failing to report a breach of confidentiality:

• Being aware of a breach of Privacy or confidentiality, but not reporting the breach to your supervisor or other designated individual.

• Not reporting that your password to a computer system has been compromised or that you have lost keys to a storage location for Confidential Information.

Appendix I

Resumé

WENDY NORDICK

1319 Sunshine Court
Kamloops, B.C.
V2E 2P9
(250) 374-5017 Home
(250) 372-0123Work
(250) 372-0123 Fax

nordickmanagement@shaw.ca

Social Work Skills

- 8 years experience in psychosocial community mental health
- 4 years experience in acute care setting, psychiatry
- Knowledge of current mental health legislation
- Superior clinical counselling skills and understanding of psychotropic medications
- Excellent psychosocial assessment: skills and documentation
- Able to create therapeutic relationships with clients, families and team members
- Outstanding case management skills
- Knowledge of psychosocial rehabilitation
- Solid knowledge of community resources
- Able to utilize outcome measures to shape best practice
- Sound assessment of crisis, mediation and conflict resolution skills
- Developing good understanding of substance abuse issues, assessment and interventions
- Growing qualitative research experience

Teaching Skills

- TRU instructor Child and Youth Diploma Program (UCC 2003), Special Topics
- TRU Field Instructor/Practicum Supervisor
- Accomplished public speaking skills (3 year Toastmaster)

General Skills

- Able to work independently, organized and take initiative
- Creative practice skills
- Good computer skills, Word, Excel, Internet, PowerPoint
- Excellent verbal and written communication skills
- Good stress management skills

- Valid BC Driver's Licence
- Current CPR certification
- Excellent physical health

Education

- PhD candidate, University of Canterbury, NZ Study: How Do I Know That I am Sick: a study on how insight is developed for people with schizophrenia
- Masters of Social Work, University of British Columbia, June 2002
- Bachelor of Social Work, University of Victoria, April 1994, Social Work Valedictorian
- Field Instructor Certification University College of the Cariboo, 2004

Professional Affiliations

- Registered Clinical Social Worker in the Province of B.C. #00-106
- Registered Rehabilitation Professional Canadian Association of Rehab Professionals #NORW0298-R

Practica

- 2001 - Weyerhaeuser Canada – Conducting a Study on Barriers to Diversity in HR Department
- 1994 - Phoenix Centre, Kamloops – Child and Youth Committee Community Study
- 1993 - University College of the Cariboo Extension Services – policy development

Work History

July 2001 to present **Royal Inland Hospital**

Social Worker: Psychiatric and Rehabilitation Wards and Children's Health Clinic

- Psychiatry: discharge planning, transition to community care, clinical work, psychosocial assessments, liaison with community agencies.
- Psychosocial assessments for suspected cases of abuse and neglect for children

December 2000- 2003 **Nordick Management Services**

Self-employed Consultant

- Mental Health disability (80% of case load)
- Medical and mental health case management
- Clinical counselling
- Community Rehabilitation Plans
- Diversity/ Work Life Balance Consulting
- Psychosocial/Vocational assessments

July 1996-November 2000 **Clarica, (Formerly the Mutual Group)**

Rehabilitation Consultant

- Mental health, medical and vocational case management
- Assess clients with functional limitations (mental and physical)
- Write and implement medical and psychosocial rehabilitation plans
- STD, LTD, auto and legal work
- Job search/labour market surveys

October 1994-July 1996 **Associative Rehabilitation /Aetna Health Management**
Rehabilitation Consultant

- Insurance rehabilitation consulting (mental and physical rehab)
- Medical and vocational case management
- Return to work planning

July 1996-August 1996 **Royal Inland Hospital Cancer Clinic**
Social Worker

- Grief and loss counselling
- Resource development

April -June 1994 **Phoenix Centre Drug and Alcohol Counselling**
Kamloops, B.C.
Social Worker

- Planning, development and promotion of Provincial Driving without Impairment Program
- Research into use of drugs and alcohol in Kamloops by women, youth and elderly

September 1991-April 1992 **UCC Dept. of Philosophy, History & Political Studies**, Kamloops, BC
Work Study Student

- Research and assist with public relations and special events

July 1974-February 1986 **City of Kamloops, Aquatic Staff (lifeguard/Lifeguard Supervisor)**

- Extensive training and teaching, supervision of large staff
- Planning and implementation of programming, budgeting and public education
- Examiner for Red Cross and Royal Lifesaving Societies

Interests

- Running, rollerblading, gardening, reading, painting and soccer

References
Available upon request

Appendix J

Interior Health

Agreement Questionnaire Scale

Insight into Insight: A study on understanding in schizophrenia

Wendy Nordick
February 2008

- Anonymous
- Approved (as not requiring further ethics application) by University of Canterbury Ethics Chairperson, February, 2008
- Used to seek input on the robustness of findings- no analysis

How much do you agree with the following statements (please check one response for each question):

Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
☐	☐	☐	☐

****

1. **The process of insight development makes sense: Chaos, Dynamic (CLARITY) and Wisdom**

Strongly Agree	Agree	Disagree	Strongly Disagree
☐	☐	☐	☐

Comments:

****

2. **This process can guide my practice**

Strongly Agree	Agree	Disagree	Strongly Disagree
☐	☐	☐	☐

Comments:

****

3. **The Trinity of Insight makes sense: Event, Meaning making of Dangerousness and Motivated Receptivity**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

Comments:

---

4. **The Trinity of Insight can guide my practice**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

Comments

---

5. **The 4 Insight constructs makes sense: interpersonal, introspective, retrospective and strategic**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

Comments:

****

6. **These 4 insight constructs can guide my practice**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

Comments:

****

7. **The Theory of Dangerousness makes sense: self construct vs. social construct**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

Comments:

****

8. **The Theory of Dangerousness can guide my practice**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

Comments:

****

9. **The Four constructions of Dangerousness make sense: preconstruction, construction, reconstruction, deconstruction**

Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree ☐

Comments:

****

10. The four constructions can guide my practice

Strongly Agree Agree Disagree Strongly Disagree

☐ ☐ ☐ ☐

Comments:

****

Any suggestions or ideas to pass along to me?

Appendix K

Agreement Questionnaire Results

Insight into Insight: A study on understanding in schizophrenia

Wendy Nordick
February 2008

Anonymous
Approved (as not requiring further ethics application) by University of Canterbury Ethics Chairperson, February, 2008
Used to seek input on the robustness of findings- no analysis

How much do you agree with the following statements (please check one response for each question):

Strongly Agree **Agree** **Disagree** **Strongly Disagree**

☐ ☐ ☐ ☐

****

1. The process of insight development makes sense: Chaos, Dynamic (CLARITY) and Wisdom

Strongly Agree	Agree	Disagree	Strongly Disagree
45%	52%	3%	0%

****

2. This process can guide my practice

Strongly Agree	Agree	Disagree	Strongly Disagree
32%	64%	4%	0%

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3. The Trinity of Crisis makes sense: Event, Meaning making of Dangerousness and Motivated Receptivity

Strongly Agree	Agree	Disagree	Strongly Disagree
41%	16%	3%	0%

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4. The Trinity of Crisis can guide my practice

Strongly Agree	Agree	Disagree	Strongly Disagree
28%	66%	7%	0%

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5. The 4 Insight constructs makes sense: interpersonal, introspective, retrospective and strategic

Strongly Agree	Agree	Disagree	Strongly Disagree
31%	66%	3%	0%

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6. These 4 insight constructs can guide my practice

Strongly Agree	Agree	Disagree	Strongly Disagree
31%	62%	7%	0%

****

7. The Theory of Dangerousness makes sense: self construct vs. social construct

Strongly Agree	Agree	Disagree	Strongly Disagree
38%	59%	3%	0%

****

8. The Theory of Dangerousness can guide my practice

Strongly Agree	Agree	Disagree	Strongly Disagree
31%	66%	3%	0%

****

9. The Four constructions of Dangerousness make sense: preconstruction, construction, reconstruction, deconstruction

Strongly Agree	Agree	Disagree	Strongly Disagree
48%	45%	7%	0%

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10. The four constructions can guide my practice

Strongly Agree	Agree	Disagree	Strongly Disagree
28%	65%	7%	0%